The Journal of Clinical Ethics

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At the Bedside

291 Do We Undervalue Feelings in Patients Who Are Cognitively Impaired?
Edmund G. Howe

302 Report of the American Medical Association Council on Ethical and Judicial Affairs: Withholding Information from Patients: Rethinking the Propriety of "Therapeutic Privilege"
Nathan A. Bostick, Robert Sade, John W. McMahon, and Regina Benjamin

307 The Grand Inquisitor's Choice: Comment on the CEJA Report on Withholding Information from Patients
Darlyn Pirakitikulr and Harold J. Bursztajn

312 The End of Therapeutic Privilege?
Nicole Sirotin and Bernard Lo

317 Comment on the CEJA Guidelines: Treating Patients Who Deny Reality
Edmund G. Howe

323 When Patients Do Not Have a Proxy: A Procedure for Medical Decision Making When There Is No One to Speak for the Patient
Inoo Hyun, Cynthia Griggins, Margaret Weiss, Dorothy Robbins, Allyson Robichaud, and Barbara Daly

Cases from the Harvard Ethics Consortium

331 A Mother's Death: The Story of "Margaret's" Children
Christine Mitchell

333 The Ethics of Palliative Care in Psychiatry
Julieta Bleichmar Holman and David H. Brendel

339 A Letter from the Children

340 Medicating "Margaret"
Coleen Reid

344 Palliative Care for "Margaret"
Rosemary Ryan

349 "Margaret's" Children Remember
Interview by Christine Mitchell

358 Attention to Caregivers and Hope: Overlooked Aspects of Ethics Consultation
Ruth B. Purtilo

364 Suffering and Advanced Dementia: Diagnostic and Treatment Challenges and Questions about Palliative Sedation
Jeffrey T. Berger

Perspectives

367 What Is False Hope?
Daniel K. Sokol

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At the Bedside

Do We Undervalue Feelings in Patients Who Are Cognitively Impaired?

Edmund G. Howe

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.[1]

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 con-

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scious 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.[2] 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.[3] 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.*[4] 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.[5] 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."[6]

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."[7]

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."[8]

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.[9]

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.[10]

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."[11] 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.[12] Their exaggerated worries may satu-

rate 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."[13]

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."[14]

The capacity to distract oneself can be taught, and the result is a state referred to as mindfulness.[15] Many chronic pain patients can experience, for example, moderate to great improvement even after only eight weeks of such training.[16] 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.[17]

Mindfulness is also wholly distinct from mere physiological relaxation.[18] 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.[19]

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.[20] 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.[21]

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.' "[22]

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."[23] 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 soci-

ety 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."[24] 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.[25]

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."[26]

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.[27] A pain-assessment measure has been developed specifically for patients with AD, although at this time it requires further testing.[28] 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.[29] 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.[30] 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.[31]

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.[32] These careproviders may alter their position when they consider when, if ever, they might make an exception to it.[33] 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.[34] 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.[35] 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.[36] 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.[37] These deficits may be evident only through formal, comprehensive, neuropsychological testing, which takes hours to carry out.[38] 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.[39]

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.[40] 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.[41] 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.[42] Some disagree; they believe that patients' capacity to feel and respond to others is most important.[43] 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."[44]

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."[45]

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.

11. W.B. Irvine, *On Desire* (New York: Oxford University Press, 2006), 84.

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.

14. J.A. Astin, "Mind-Body Therapies for the Management of Pain," *Clinical Journal of Pain* 20, no. 1 (January/February 2004): 27-32, 31.

15. Ibid.

16. Ibid., 29.

17. J. Kabat-Zinn, L. Lipworth, and R. Burney, "The Clinical Use of Mindfulness Meditation for the Self-Regulation of Chronic Pain," *Journal of Behavioral Medicine* 8, no. 2 (1985): 163-90, 186.

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

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

20. C. Tiberti et al., "Prevalence and Correlates of the Catastrophic Reaction in Alzheimer's Disease," *Neurology* 50, no. 2 (February 1998): 546-8.

21. Aggression occurs most often during intimate care, possibly because the person feels most vulnerable. R.T. Woods, "Discovering the Person withAlzheimer's Disease: Congnitive, Emotional, and Behavioural Aspects," *Aging and Mental Health* 5 (supp. 1): S7-16, 12.

22. R. Dickinson, "Taking a Stand Against Fear," *Nursing* 34, no. 9 (September 2004): 43.

23. G.E. Moore, *Principia Ethica* (New York: Prometheus Books, 1998), 28.

24. T. Kitwood, "Positive Long-Term Changes in Dementia: Some Preliminary Observations," *Journal of Mental Health* 4, no. 2 (April 1995): 133-44, 134.

25. M. Rowley, "Fresh Voices: My Grandma Didn't Recognize Me," *Parade Magazine,* 15 January 2006, 8, at *http://www.parade.com/ articles/editors/2006/edition-01-15-2006/Fresh-Voices.*

26. A. Thomas, *A Three Dog Life* (Orlando, Fl.: Harcourt, 2006), 162.

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.

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

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.

Report of the American Medical Association Council on Ethical and Judicial Affairs: Withholding Information from Patients: Rethinking the Propriety of "Therapeutic Privilege"

Nathan A. Bostick, Robert Sade, John W. McMahon, and Regina Benjamin

INTRODUCTION

Some physicians have withheld medical information from patients when they have believed full disclosure to be medically contraindicated, to avoid potential harm to the patient's physical or psychological well-being. This practice, commonly referred to as "therapeutic privilege," is distinct from circumstances when it is not feasible to disclose information to a patient, such as emergency situations or other instances when a patient lacks the capacity of making decisions.[1] It also is distinct from disclosure issues that arise from medical errors, which the American Medical Association Council on Ethical and Judicial Affairs (CEJA) has addressed in a previous report.[2]

Intentionally withholding information may be viewed as presenting a conflict between a physician's ethical imperative to protect patients and a physician's ethical obligation to be truthful and to provide patients with relevant medical information. Moreover, it abrogates the process of shared decision making and conflicts with contemporary expectations that physicians will respect patients' autonomy and enable them to take an active role in making treatment decisions that reflect their interests and prefer-

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ences. It is in this context that this report reexamines the ethical propriety of withholding medical information from patients.

ETHICAL ANALYSIS

Nondisclosure of medical information was once uncontroversial, when paternalism afforded physicians broad discretion in making treatment decisions on behalf of their patients. Stemming from the Hippocratic tradition, physicians were ethically obligated to promote their patients' welfare by providing care in accordance with their own judgment regarding the most appropriate course of treatment.[3] Physicians could opt not to share potentially distressing diagnostic or prognostic medical information with patients if they believed that disclosure might prove detrimental to patients' well-being.[4] Accordingly, the selective withholding of medical information could be viewed as fulfilling physicians' obligations both to act beneficently[5] and to promote patients' overall well-being.[6]

This practice of nondisclosure was well established in the foundational works of Western medical ethics, such as Percival's *Medical Ethics,* which promoted the beneficent withholding of medical information to minimize patients' distress.[7] Similarly, the 1847 American Medical Association (AMA) *Code of Medical Ethics* stated that physicians had a "sacred duty . . . to avoid all things which have a tendency to discourage the patient and depress his spirits."[8] These guidelines helped to establish legal precedents that allowed physicians to withhold potentially harmful information from their patients, in the event that full disclosure would impede patients' abilities to render rational decisions or harm them in other ways.[9]

In recent decades, medical paternalism has given way to the contemporary concepts of patient autonomy and shared decision making.[10] Today, physicians are called upon to promote patients' well-being by openly discussing the balance between anticipated benefits of a given intervention and its potential harms.[11] In some instances, a case-specific balance of benefits and harms may appear to some physicians as justification to withhold medical information, with the beneficent desire to protect patients from potential harms. However, a physician's concealment of medical information may not prove beneficent if it contravenes a patient's own wishes.

Many patients want detailed medical information, even if it means receiving adverse diagnostic or prognostic information.[12] Physicians' communication of detailed medical information has been shown to ease patients' anxiety and improve health outcomes.[13] Moreover, increased levels of communication and sharing of information may also contribute to higher levels of patients' satisfaction[14] and potentially decrease malpractice liability.[15] Conversely, the lack of adequate information may preclude patients from receiving necessary medical attention or making optimal life decisions on the basis of their individual needs and personal values.[16]

Withholding pertinent medical information from patients without their knowledge or consent may also have negative long-term consequences for the medical profession. The patient-physician relationship is founded upon trust, because patients must rely upon their physicians to provide the information needed to make a properly informed decision.[17] Lack of candid disclosure can compromise this relationship if patients suspect (or later discover) that information is being withheld from them.[18] Thus, individual physicians' purportedly benevolent acts of deception risk undermining not only individuals, but also public confidence and trust in the medical profession.[19]

In practice, medical information should never be permanently withheld from the patient because doing so represents a clear violation of patients' trust. However, physicians' obligation of beneficence may allow (or compel) them to postpone the full disclosure of information to patients whose capacity to make competent medical decisions may be compromised, or when disclosure is otherwise medically contraindicated.[20] Delayed disclosure, however, is not justified when physicians merely intend to prevent a patient's refusal of medically neces-

sary treatments,[21] or to instill hope for the future.[22]

Little is known of the extent to which disclosure of alarming medical information may ultimately harm patients.[23] Physicians are encouraged to consult colleagues or hospital ethics committees when considering the need to temporarily withhold medical information from their patients. Such consultations reflect respect for patients' right of self-determination and can be of real help to physicians in assessing available alternatives to postponement of communicating medical information.

When physicians determine that a patient should not receive all relevant medical information at a given time, they need to continue to provide appropriate care for and monitor the patient to identify an appropriate time to offer full disclosure. This should be done according to a definite plan, so that disclosure is not permanently withheld.

PROMOTING PATIENT-PHYSICIAN COMMUNICATION

Physicians' concerns about disclosure of potentially harmful information should lead them to encourage patients to make choices regarding the receipt of medical information before potentially harmful information becomes available.[24] Physicians should tailor their disclosure of medical information in response to the needs, expectations, and preferences of individual patients.[25]

To respect patients' rights of decisional autonomy, physicians must offer all patients the opportunity to receive relevant medical information.[26] This may be accomplished by asking patients to specify the scope of information they wish to receive and their preferred methods for receiving it. Physicians should then honor these preferences to the extent practicable.

Some patients may want certain medical information to be withheld.[27] Others may wish to involve family members in the decision-making process or, alternatively, to appoint family members or trusted caregivers to act as their proxy.[28] Physicians should respect the wishes of competent patients, including accommodation of their cultural and religious beliefs.[29] However, physicians should consider patients' decisions sensitively to ensure that their requests are not coerced and genuinely represent the patients' preferences.[30] Additionally, physicians should educate patients and their proxies about the importance of disclosure and shared decision making.[31]

When communicating medical information, physicians should assess the amount of information that patients want and are capable of receiving at a given time.[32] Clinical judgment is required to determine the appropriate means for communicating relevant information, taking patients' personalities and clinical histories into account when possible.[33] Information should be presented in a way that patients can understand and use in making medical decisions.[34] Finally, physicians should attempt to confirm that this information has been understood — for example, by asking them to repeat what they have been told — and providing further clarification as necessary.[35]

Physicians should communicate all requested medical information sensitively and respectfully,[36] while seeking to minimize any negative effects upon the patient.[37] By listening to patients' concerns and responding to their individual need, physicians can promote the patient-physician relationship[38] and protect against the iatrogenic suffering of patients.[39] Physicians can also minimize potential harms by monitoring patients' well-being and by helping them to access appropriate support services, when needed.[40]

CONCLUSION

Withholding relevant medical information from patients without their knowledge or consent, in an attempt to minimize potential physical or psychological harms, has been called "therapeutic privilege." This practice creates a conflict between physicians' concurrent obligations to act beneficently and to respect patients' autonomy. Whenever possible, physicians should minimize the withholding of medical

information by accommodating patients' preferences.

RECOMMENDATIONS

Withholding pertinent medical information from patients under the belief that disclosure is medically contraindicated, a practice known as "therapeutic privilege," creates a conflict between the physician's obligations to promote patients' welfare and respect for their autonomy by communicating truthfully. Therapeutic privilege does not encompass withholding medical information in emergency situations, or reporting medical errors (see E-8.08, "Informed Consent," and E-8.121, "Ethical Responsibility to Study and Prevent Error and Harm").

Withholding medical information from patients without their knowledge or consent is ethically unacceptable. Physicians should encourage patients to specify their preferences regarding communication of their medical information, preferably before the information becomes available. Moreover, physicians should honor patient requests not to be informed of certain medical information or to convey the information to a designated proxy, provided these requests appear to genuinely represent the patient's own wishes.

All information need not be communicated to the patient immediately or all at once; physicians should assess the amount of information a patient is capable of receiving at a given time, delaying the remainder to a later, more suitable time, and should tailor disclosure to meet patients' needs and expectations in light of their preferences.

Physicians may consider delaying disclosure only if early communication is clearly contraindicated. Physicians should continue to monitor the patient carefully and offer complete disclosure when the patient is able to decide whether or not to receive this information. This should be done according to a definite plan, so that disclosure is not permanently delayed. Consultation with patients' families, colleagues, or an ethics committee may help in assessing the balance of benefits and harms associated with delayed disclosure. In all circumstances, physicians should communicate with patients sensitively and respectfully.

NOTES

CEJA formulates ethical policies for the medical profession and maintains the 160-year-old *American Medical Association Code of Medical Ethics.* This article is based on the CEJA policy report, "Withholding Information from Patients," which was approved by the AMA House of Delegates in June 2006. The recommendations of this report are now included among the official ethics policies of the American Medical Association.

1. CEJA Opinions E-8.08, "Informed Consent" and E-8.081, "Surrogate Decision Making," *http://www.ama-assn.org/go/cejareports,* or call (312) 464-4823.

2. CEJA Opinion E-8.121, "Ethical Responsibility to Study and Prevent Error and Harm," *http://www.ama-assn.org/go/cejareports,* or call (312) 464-4823.

3. A. Meisel, "The 'Exceptions' to the Informed Consent Doctrine: Striking a Balance Between Competing Values in Medical Decision Making," *Wisconsin Law Review* (1979): 413-88, p. 460, n. 153.

4. D. Novack et al., "Physicians' Attitudes Toward Using Deception to Resolve Difficult Ethical Problems," *Journal of the American Medical Association* 261, no. 20 (1989): 2980-5.

5. Ibid.

6. B. Barber, *Informed Consent to Medical Therapy and Research* (New Brunswick, N.J.: Rutgers University Press, 1980), 37.

7. P.R. Wolpe, "The Triumph of Autonomy in American Bioethics: A Sociological View," in *Bioethics and Society,* ed. R. Devries and J. Subedi (Upper Saddle River, N.J.: Prentice Hall, 1998), 39.

8. R. Boyle, "Communication, Truthtelling, and Disclosure," in *Introduction to Clinical Ethics,* 2nd ed., ed. J. Fletcher et al. (Hagerstown, Md.: University Publishing Group, 1997), 56-7.

9. 464 F.2e 772 (D.C. Cir 1972); *Natanson v. Kline,* 350 P.2d 1903 (Kan. 1960).

10. CEJA Opinion E-8.08, "Informed Consent," see note 1 above.

11. CEJA Opinion E-10.015, "The Patient-Physician Relationship," *http://www.ama-assn.org/go/cejareports,* or call (312) 464-4823.

12. M. Marzanski, "Would You Like to Know What is Wrong with You? On Telling the Truth to Patients with Dementia," *Journal of Medical Ethics* 26 (2000): 108-13; M. Silverstein et al., "ALS and Life-Sustaining Therapy: Patients' Desires for Information, Participation in Decision-Making, and Life-Sustaining Therapy," *Mayo Clinic Pro-*

ceedings 66 (1991): 906-13.

13. See note 8 above.

14. S. Kaplan et al., "Characteristics of Physicians with Participatory Decision-Making Styles," *Annals of Internal Medicine* 124 (1996): 497-504.

15. W. Levinson, "Physician-Patient Communication: A Key to Malpractice Prevention," *Journal of the American Medical Association* 272 (1994): 1619-20.

16. P. Herbert et al., "Bioethics for Physicians: 7. Truth Telling," *Canadian Medical Association Journal* 156, no. 2 (1997): 225-8; J. Weeks et al., "Relationship between Cancer Patients' Predictions or Prognosis and Their Treatment Preferences," *Journal of the American Medical Association* 279, no. 21 (1998): 1709-14.

17. CEJA Opinion E-10.01, "Fundamental Elements of the Patient-Physician Relationship," *http://www.ama-assn.org/go/cejareports,* or call (312) 464-4823.

18. J. Conn, M. Gillman, and S. Conway, "Ethics in Practice: Revealing the Diagnosis of Androgen Insensitivity Syndrome in Adulthood," *British Medical Journal* 331 (2005): 628-30.

19. S. Bok, *Lying: Moral Choice in Public and Private Life* (New York: Vintage Books, 1979), 28.

20. A. Cote, "Telling the Truth? Disclosure, Therapeutic Privilege and Intersexuality in Children," *Health Law Journal* 8 (2000): 199-216.

21. M. Wynia, "Invoking Therapeutic Privilege," *AMA Virtual Mentor,* accessible at *http://www.ama-assn.org/ama/pub/category/print/11937.html.*

22. G. Annas, "Informed Consent, Cancer, and Truth in Prognosis," *New England Journal of Medicine* 330 (1994): 233-5.

23. R. Buckman, *How to Break Bad News: A Guide for Health Care Professionals* (Baltimore: Johns Hopkins University Press, 1992), 53.

24. E. Patterson, "Therapeutic Justification for Withholding Medical Information: What You Don't Know Can't Hurt You, or Can It? *Nebraska Law Review* 65 (1985): 721.

25. W. Weston, "Informed and Shared Decision-Making: The Crux of Patient-Centered Care," *Canadian Medical Association Journal* 165, no. 4 (2001): 434-9.

26. B. Freedman, "Offering Truth: One Ethical Approach to the Uninformed Cancer Patient," *Archives of Internal Medicine* 153 (1993): 572-6.

27. D. Pietsky, "The Breakthrough," *Annals of Internal Medicine* 124 (1996): 345-7.

28. A. Surbone, "Letter from Italy: Truth Telling to the Patient," *Journal of the American Medical Association* 268 (1992): 1661-2.

29. E. Etchells et al., "Bioethics for Clinicians: 2. Disclosure," *Canadian Medical Association Journal* 155 (1996): 387-91.

30. See Herbert et al., note 16 above.

31. Ibid.

32. British Medical Association, *Human Genetics, Choice and Responsibility* (Oxford: Oxford University Press, 1998), 86-8.

33. See note 4 above.

34. See Herbert et al., note 16 above.

35. D. Schillinger et al., "Closing the Loop: Physician Communication with Diabetic Patients Who Have Low Health Literacy," *Archives of Internal Medicine* 163, no. 1 (2003): 83-90; National Quality Forum, *Implementing a National Voluntary Consensus Standard for Informed Consent: A User's Guide for Healthcare Professionals* (Washington, D.C.: National Quality Forum, 2005).

36. J. Jackson, "On the Morality of Deception — Does Method Matter? A Reply to David Bakhurst," *Journal of Medical Ethics* 19 (1993): 183-7.

37. G. Weiss, "Patients' Rights: Who Should Know What?" *Medical Economics* 19 (2002): 97.

38. See note 23 above, p. 11.

39. Da Silvia et al., "Not Telling the Truth in the Patient-Physician Relationship," *Bioethics* 17 (2003): 417-24.

40. See note 23 above.

The Grand Inquisitor's Choice: Comment on the CEJA Report on Withholding Information from Patients

Darlyn Pirakitikulr and Harold J. Bursztajn

Historically, paternalism had been the accepted norm in doctor-patient relationships. By virtue of their knowledge and experience, doctors decided what treatment was in the best interests of patients. However, in recent years, medicine has changed from a predominantly paternalistic profession to one that is more patient-centered. The physician informs and advises the patient, but it is the patient who makes the decision. Given this evolution, the physician's dual duties of promoting the patient's health while supporting the patient's autonomy, by providing pertinent medical information, can at times become a balancing act. The physician must weigh, on the one hand, the value of the patient's liberty to make personal medical choices based on full disclosure of relevant information, and, on the other, the patient's health, which in rare instances might be compromised by full disclosure.

While instances of a patient's autonomy and health interests coming into conflict are often more apparent than actual, such instances have on occasion been dramatic. Moreover, due to the synergy of cognitive heuristics, emotional dynamics, and the socioeconomic forces that form the subtext of today's medical practices, such conflicts can be easily overestimated, so as to rationalize the expediency of silence — which can be conducive to seeing more patients in less time (in keeping with reimbursement patterns), as well as to avoid the moments of awkward angst, the emotional turmoil, which enters doctor-patient encounters when there is awareness of the transience of human existence. Thus the enduring temptation of withholding information and avoiding choices, as in the offer made by The Grand Inquisitor in Dostoevsky's *The Brothers Karamazov.* The Grand Inquisitor promises man everything in exchange for the one thing that makes him human: free will to choose or reject at any time what his conscience tells him is a moral good.[1] While the patient's well-being is certainly a priority, if the physician denies the patient liberty,

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the physician is in effect denying the patient free will, which is essential to being human.

While classically there has been a position of clinical silence on upsetting patient news,[2] in the "Report of the American Medical Association Council on Ethical and Judicial Affairs: Withholding Information from Patients: Rethinking the Propriety of 'Therapeutic Privilege'," the AMA concludes that fundamentally withholding information from patients without their knowledge or consent is unacceptable, yet leaves a loophole for the persistent temptation to rationalize nonetheless doing so. The loophole rests on the reasonable-appearing proposal that physicians ascertain patients' preferences regarding the communication of their medical information, preferably before that information becomes available. It allows clinicians to delay the release of information in cases when they infer that would be the patient's preference or when a patient's preference for delay in being informed of upsetting information had been previously elicited.

The AMA proposal is well intended. However, its practical applicability must be taken into account. In what follows, we explore three areas of concern. The first deals with patients in pain and their need to have more time and support for any informed-consent process to be meaningful. The second is the fact that a managed-care-dominated climate has left physicians under enormous time pressures. The amount of face-to-face time physicians spend with patients has markedly decreased, with physicians instead spending more time on administrative burdens. Introducing the new AMA guidelines in such an environment lends itself to *pro forma* informed consent (going through the motions) rather than meaningful informed consent. Finally, the third issue we have identified is the extent to which information needs to be provided to physicians by drug and device manufacturers in a forthright manner, since initial misrepresentations or unsupported claims of efficacy and safety are difficult to correct in clinical practice and foster the clinical temptation to invoke therapeutic privilege as a rationalization.

The AMA guidelines call for physicians to ascertain patients' preferences for receiving medical information before such situations arise. Without knowledge about the future, physicians are asked to elicit preferences for information regarding scenarios that are difficult to imagine. This is all the more difficult because people are generally not good at anticipating their future preferences, even when facing mundane experiences.[3] The end result is likely not to meet the expectations of a reasonable patient to be informed in a reasonable and supportive manner.[4] Furthermore, the cognitive heuristics that people use to process large amounts of information efficiently, such as conservatism in updating their initial impressions and probabilities, have their pitfalls, such as premature cognitive commitment — that is, the tendency to come to conclusions based on insufficient data. To recognize these human factors in information processing is to conclude that full and meaningful disclosure is needed from the outset. Thus the AMA loophole for sequential disclosure under the rationalization of a plan for future disclosure needs to be closed. Not to close this loophole is to risk that the new guidelines will all-too-often become in practice, old wine in a new bottle.

It also needs to be explicitly recognized that patients who suffer — as those in pain, anxiety, depression, or in the shadow of the awareness of the transience of our existence do — require more time and support for the informed-consent process to be meaningful. Obtaining meaningful informed consent requires care and time because of variations in patients' capacity for understanding and the complexities of health conditions. At one extreme, some claim,

> When a person is in extreme pain, truly informed consent may not be possible. Caregivers have an ethical obligation to inform the capacitated patient about the salient effects and side-effects, benefits and risks of pain management options, especially those related to use of narcotics, to help the patient to reach an informed decision about treatment. But, despite the best efforts to

> provide relevant information and elicit the patient's values and wishes, severe pain may erode an individual's cognition and autonomy. A patient suffering such pain often can think of nothing except relief and will agree to anything that will provide it. For such patients, truly free and informed consent may be an illusion.[5]

However, it is a mistake to thereby throw out the baby with the bath water and, under the cloak of therapeutic privilege, to avoid informed-consent processes altogether or go through the motions of only a *pro forma* informed-consent process.[6] The capacity of people in pain to make decisions — when given support, time, multiple visits, and meaningful information regarding risks, benefits, and alternatives — can be enhanced. A meaningful discourse can lead to a therapeutic alliance. A therapeutic alliance is a vital social matrix for meaningfully and helpfully sharing uncertainty and helping a patient bear pain without the compounding bitterness, helplessness, and hopelessness that accompany aloneness. Thus, more often then not, the conflict between autonomy and health is more an artifact of our rush in the clinic and our own incorrigibility than a fact of nature or the patient's incorrigibility.

Another issue to address is whether introducing the new AMA guidelines in the age of managed care will lead to *pro forma* consent rather than meaningful informed consent. Managed care has greatly changed the practice of medicine. Physicians are now under enormous financial and time constraints, and personal one-on-one doctor-patient relationships have been replaced by brief doctors' visits. As a result, instead of real relationships, doctors are finding themselves in mere contractual arrangements with other physicians, health-maintenance organizations, and the public.

In this time-strapped environment, the AMA proposal to obtain information about a patient's preferences for receiving medical information before that information is available would most likely be implemented in the form of a survey or form that the patient would have to fill out and sign upon visiting a physician. Because the *pro forma* signing of a consent form does not constitute informed consent,[7] it is necessary that such a form be fully explained to the patient, that the patient have an opportunity to ask questions, and that there be some sort of acknowledgment that the patient appreciates the implications of what he or she has just signed. In short, a substantial amount of time needs to be devoted to obtain true informed consent regarding information preferences, especially for frightened patients who face pain and uncertainty — an amount of time that is unlikely to be available in the age of managed care.[8]

From a risk-management perspective, we are learning that patients and juries value informed consent far more than managed-care companies do.[9] If adequate time and care are not given to this process, and if the patient signs the form without fully knowing its implications, the AMA regulations could, in effect, be used by physicians as a Trojan horse to excuse failure to obtain informed consent for certain treatments and procedures. Such rationalizations do not ensure either quality clinical care or adequate risk management. In many institutions, a liaison of sorts is appointed, whose sole purpose is to explain the informed-consent form to patients. Yet even in such a setup, the pervasive issues of time and cost remain. Moreover, the designated informed-consent liaison often lacks the meaningful authority and relationship with the patient to make informed consent a meaningful process.

Occasions when drug and device manufacturers withhold information from physicians are as troubling as the rationalization that information should be withheld or delayed in the name of therapeutic privilege. This is typically done out of the fear that negative studies could lead doctors to prematurely reject a treatment, and for competitive reasons — drug companies argue that such studies are trade secrets and therefore should not be available to the public. This creates a distorted scientific record that physicians must use to make clinical judgments. Keeping data secret has led to conflicting information, contradictory advice, and heightened

fears, and the end result is that physicians are deprived of information they need to evaluate the risks and benefits of prescribing a course of treatment.

When drug and medical device manufacturers do not disclose full information about their products, physicians may be privy to only limited information, and they may not even be aware that they are operating with limited information. Delayed disclosure does not undo damage caused by an initial misrepresentation, as the first clinical impressions are often the last impressions.[10] While conservatism can be a useful heuristic to frugally manage a flood of incoming data so that it does not sweep away prior information, it has its pitfalls. These become readily apparent when, given people's inherent conservatism and disinclination to change their minds, an initial misrepresentation of efficacy or risk by a manufacturer leads to a persistent lack of truly informed consent by patients. While physicians do have an obligation to be truthful to their patients, it can be difficult for a physician to acknowledge to a patient that the physician has been fooled by a pharmaceutical manufacturer's marketing that misrepresented efficacy or discounted risk. Under such conditions, it may become too tempting to rationalize and opt to not upset a patient and delay informing a patient under the guise of therapeutic privilege, and to accede to a preference previously elicited from the patient to avoid upsetting information.

While we have primarily focused on three issues in our discussion of the proposed AMA guidelines, there are a number of other potentially significant issues. One such issue is the disclosure of information concerning medical errors, which is explicitly excluded from these proposal guidelines. A survey of more than 2,600 surgeons and medical specialists recently published in the *Archives of Internal Medicine* revealed that there are wide variations in doctors' willingness to disclose errors and in the ways they would present the details to patients.[11] These errors ranged from the obvious to non-obvious, and the study noted that when error was not obvious, doctors were sometimes unwilling to disclose it, as patients might not have enough knowledge to fully understand the nature of the error that took place and as a result might be frightened unnecessarily. Physicians also expressed concern that patients often assume any adverse event is an error, when in reality the majority of adverse events are not errors and are unpreventable.

Such a climate of distrust of patients by physicians as the survey reveals is a sad commentary on what is endangered when medical care becomes less caring and more focused on time and the management of appearances. To foster an environment of trust and openness with patients, it is important for physicians to disclose potentially upsetting information such as their own potential financial conflicts, including indirect but subtle conflicts of interest such as industry support of advisory panels and departments of academic medicine. Yet such disclosure is all-too-often resisted, even in contexts outside patient care. A recent study reports that, of 170 members of a DSM [Diagnostic and Statistical Manual of Mental Disorders] panel who were investigated for possible conflicts of interest, 56 percent were found to have strong financial ties with the pharmaceutical industry. Moreover, the study found strong ties between the pharmaceutical industry and those who were responsible for developing and modifying diagnostic criteria for mental illness, and these connections were especially strong in diagnostic areas in which medications are the first line of treatment for mental disorders.[12] While such relationships may be entirely legitimate, and may not imply any wrongdoing on the part of physicians, an impression of wrongdoing may arise if the relationships are left undisclosed. The participation of academic researchers in clinical trials and their consultation with the pharmaceutical industry can be beneficial to the care of patients, but it is critically important to define and enforce the boundaries between promotional activities and the unbiased presentation of clinical and scientific information.[13]

Ultimately, therapeutic privilege is all-too-often a misnomer. Withholding information is not a privilege, as it burdens the doctor-patient

alliance. If the term "therapeutic privilege" has any meaning, it is only because it is exercised after carefully listening to the patient. The doctor-poet William Carlos Williams spoke of "the poem which their [patients'] lives are being lived to realize." Mechanical adherence to prosaic guidelines is no substitute for caring and for listening to the poem of our patients' lives.[14]

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DISCLAIMER

Harold Bursztajn has served as both a plaintiff and defense-retained consulting and testifying expert, as well as an advisor to the judiciary in informed consent and pharmaceutical and medical product liability class action cases.

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The End of Therapeutic Privilege?

Nicole Sirotin and Bernard Lo

Truth-telling and good communication are essential components of a trusting (and trustworthy) doctor-patient relationship. The AMA guidelines, "Withholding Information From Patients: Rethinking the Propriety of 'Therapeutic Privilege'," provide clear and thoughtful justification for disclosing health information to patients. These new AMA guidelines sharply narrow "therapeutic privilege," defined as the practice of withholding information from patients when disclosure is deemed to be medically contraindicated or to avoid potential physical or psychological harm to the patient. If MDs withhold health information from patients, they need to provide a convincing justification. This is a stark change from the historical practice that a physician's duty included the beneficent withholding of information for the sake of the patient. The presumption now in the AMA guidelines is "to offer all patients the opportunity to receive relevant medical information." Medical information should never be permanently withheld from a patient, although there are situations when postponement or a step-wise approach to disclosure may be more appropriate. In addition, the guidelines suggest that patient-physician communication can be enhanced by asking patients how much information they would like and how it should be delivered. This approach allows the physician to respect the wishes of the patient concerning withholding information. Although the recommendations are clear, physicians still need more specific guidance. What harm or "medical contraindication" would justify withholding information? To date, most discussions have concerned withholding the diagnosis of cancer from a patient from a cultural background where such diag-

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noses are not usually disclosed.[1] The following two cases illustrate additional dilemmas regarding disclosure and suggest how to resolve the practical issues that physicians face when implementing the AMA guidelines. Physicians may find it useful to organize their approach around a series of questions (see table 1): Whether to disclose? Who should disclose? When to disclose? Where to disclose? What to say to the patient?

THE PATIENTS

CASE 1

Ms E. is a 67-year-old African-American woman brought in by ambulance to the emergency department (ED) at a busy public hospital after a bus accident. She was found to have a dislocated shoulder, which was reduced. Because the patient also reported vague abdominal pain, a CT [computed tomography] scan of the abdomen and pelvis was obtained. The scan revealed no evidence of trauma, but diffuse masses consistent with metastatic disease were seen.

Ms E. was terrified and repeated, "I'm in pain, I'm in pain." She had trouble answering questions because of her distress. The ED staff became frustrated and felt she needed to cooperate more with the history taking. After receiving opioids for pain, Ms E. remained agitated. She was given promethazine. She then became drowsy and slightly confused.

Because Ms E. was brought into the ED as a trauma patient, she was placed in one of the trauma bays, which had bright lights, deafening noise, and many people coming in and out. She repeatedly asked for her belongings and stated that she did not feel secure. A physician who was involved with her care from the beginning decided to tell Ms E. the results of the CT scan. Asking further information about Ms E.'s medical history, the doctor learned that Ms E. had been diagnosed with breast cancer 10 years ago. The physician started by saying, "I have something to tell you about your CT scan. There is no sign of injury from the accident, but I am afraid there were multiple spots seen on the scan. I think this might be cancer." Ms E. was appropriately stunned by this information. She stated that she would stay to have this further evaluated.

A few hours later, after the physician who told her this information finished her shift, Ms E. left the emergency room against medical advice.

CASE 2

Mr. G. is a 35-year-old man who was admitted to the ICU [intensive care unit] with respiratory failure requiring ventilator support after an overdose as a suicide attempt. An HIV viral load was mistakenly ordered and the result was consistent with active HIV infection. Mr. G was critically ill and was not improving on broad-spectrum antibiotics. No microbial information was available and, due to the HIV+ test, he was presumed to be immunocompromised. A bronchoscopy was performed and revealed an infection with *Pneumocystis carinii* pneumonia. The patient was treated appropriately, but was difficult to wean off the ventilator. The patient was extremely anxious and spent many days awake, intubated, and repeatedly failed spontaneous breathing tri-

TABLE 1 Considerations for Disclosing Information and Strategies for Physicians to Address Them

Considerations for Disclosure	Strategies for Physicians
Who discloses the information	Physician with most long-standing, trusting relationship with patient should disclose the information
Where to disclose	Create a private, quiet setting for disclosure Delay complete disclosure until optimal setting is obtained
When to disclose	Assess patient's ability to cope with information Address barriers to understanding and coping
What to say to the patient	Determine patient's readiness for information Fit pace of disclosure to patient Use simple, unambiguous language Provide empathy and support

als. An HIV test was offered and declined by the patient. Attempts to find a surrogate decision maker were unsuccessful. Due to Mr. G.'s extreme anxiety, the team decided to wait until he was extubated and less anxious to disclose his HIV status. After the patient was extubated, the team told the patient the HIV test was inappropriately ordered and disclosed the results. The patient then told the team that his former partner had just died of an AIDS-related illness and that his grief and fear of his own HIV status both contributed to his suicide attempt.

DISCLOSE OR NOT?

The reasons for offering to disclose information to patients are summarized in table 2. Most patients want to know their diagnosis, even if it is unfavorable.[2] They need full disclosure of their diagnosis or condition to move forward with decision making and planning for the future. In addition, once a piece of information is withheld, more deception is often required to keep it from the patient. For example, if a child would like to keep the diagnosis of cancer from an ailing parent, healthcare workers need to provide the patient another explanation of illness. In reality, to keep a diagnosis from a patient is often impossible. Many members of the healthcare team will be directly involved with the patient but will not be aware of the decision to withhold information.

These cases suggest the type of harms that might justify withholding information from patients, at least partially or temporarily. In these cases, disclosure might lead directly to serious, immediate harm to the patient. In case 2, the patient's suicide attempt suggests severe mental illness and a danger that disclosure of an incurable illness might lead the patient to harm himself or others. Furthermore, anxiety was making extubation more difficult. Under these circumstances, disclosure may be postponed until the patient is extubated and further psychiatric assessment can be obtained. In case 1, the patient's anxiety, pain, and mistrust of her surroundings was exacerbated by the commotion in the emergency department. While the patient was not known to have a serious psychiatric condition, the physicians appropriately considered how to optimize the timing and setting of disclosing her serious medical condition. In other cases, a patient may specifically state that he or she does not want to know the medical information. The physician must be confident that the patient has the capacity to make that decision and is not being influenced by family or friends.

These principles are detailed in the AMA guidelines and elsewhere,[3] but we will discuss more practical issues and offer strategies for resolving difficult scenarios. The physician must evaluate the reasons to withhold or disclose information. Once the decision has been made to tell the patient the information, a framework for approaching disclosure includes deciding who will tell the patient, when, in what setting and what will be said during the disclosure (see table 1). Using our cases, we will highlight practical strategies that clinicians can use when they are confronted with difficult scenarios involving disclosing information.

WHO SHOULD DISCLOSE?

Ideally the patient's primary careprovider or a physician with a long-standing relationship with the patient should disclose a serious diagnosis to the patient. If that is not possible, as in the case with Ms E., the team member who dis-

TABLE 2 Considerations for Whether to Withhold Information

Reasons to disclose information
Most patients want to know
Patients' need for information for decision making
Deception requires more deception
Might be impossible to keep the information from the patient
Reasons for withholding information
Prevent harm
Not culturally appropriate
Patient does not want to be told

Source: B. Lo, *Resolving Ethical Dilemmas: A Guide for Clinicians,* 3rd ed. (Philadelphia: Lippincott Williams & Wilkins, 2005), 45-56.

cusses the diagnosis should be the one who is most available to spend time with the patient, answer all of her questions, and provide support. When a patient from an ethnic minority group mistrusts the medical system, involving a healthcare worker from a similar cultural background can be helpful. If a nurse has the best relationship with the patient, he or she should be present when a physician discloses the CT results. If the patient is going to be admitted to the hospital, the in-patient team, who will develop a relationship with the patient, is better suited than the ER staff to disclose an incidentally found, serious diagnosis. In the case of Mr. G., most ICUs use a team-based approach in which different people care for patients on different days, rather than one primary individual. In this case also, the person with the most trusting relationship with the patient should disclose information to the patient.

WHEN TO DISCLOSE?

The timing of disclosure is crucial. The physician should consider the patient's readiness to absorb information, in addition to what is happening around the patient at the time of disclosure. It may be desirable to defer disclosure until reversible barriers to good communication have been overcome. In the case of Ms E., specific issues that should be addressed include pain, the central nervous system side-effects of medications, and anxiety. In the case of Mr. G., his suicide attempt and his anxiety at being on a ventilator were pertinent concerns. Disclosure of his HIV status was postponed until he was extubated and psychiatric consultation was obtained.

WHERE TO DISCLOSE?

Neither the ER nor the ICU is an ideal place for a private, sensitive conversation. Yet simple measures can help create a calm, confidential environment. These include closing doors or curtains, turning off alarms, and obtaining comfortable seating that allows level eye contact with the patient. Pagers should be turned to silent or given to a colleague. Ancillary staff should be informed that there is going to be an important discussion and should be asked to avoid unnecessary interruption.

WHAT TO SAY TO THE PATIENT?

As physicians, the words we choose to use can help patients understand and cope with bad news.[4] In the case of Mr. G., the physicians could have started by evaluating Mr. G.'s own assessment of his situation: "Mr. G., what is your understanding of your condition?" This open-ended question should elicit the patient's fears regarding HIV infection. This information would help the team disclose his HIV test results. Next, the physician can ascertain the patient's readiness to hear the information with a warning that bad news is coming: "Ms E., I am afraid I have some bad news. Do you feel like talking now?" This could be followed with a step-wise approach to disclosure based on how much information Ms E. wanted to hear at that time. Telling Ms E. that something serious was seen on her CT scan, that needs further medical attention, imparts the seriousness of the condition without overwhelming her with information.

In the case of Mr. G., it was essential to admit that the test was sent in error. "A test was sent by mistake that gives us important information about your health. We apologize for sending for this test without your knowledge. Now that we have the results, we would like to discuss them with you. Would you like to do that now?" Ideally, ascertaining the patient's preferences regarding information happen before a test is ordered, but this approach can be used for incidental findings, tests sent in error, or other situations in which discussions before the test are impossible.

When partial disclosure is chosen, a plan must then be put in place for full disclosure. At that later time, it is best to use simple, unambiguous, lay terms such as, "I'm sorry that the CT scan shows some bad news. I'm afraid you might have cancer." Keeping the information simple and concise will allow the patient to absorb what she or he can. The physician should then pause, allow the patient to react, and then address the patient's immediate concerns. As

in all sensitive interactions, it is important to show empathy and support, and to reassure the patient that she or he will receive the best care possible.

HOW SHOULD SPECIAL ISSUES BE ADDRESSED?

Our two cases raise unusual concerns that deserve additional comment. If a patient leaves the hospital against medical advice after hearing of a serious diagnosis, as occurred with Ms E., steps should be taken to attempt to keep her in care. The ER can make a follow-up telephone call or send a letter to the patient or to the patient's primary physician. The case of Mr. G. was complicated because the HIV antibody test was sent by mistake. The error should be disclosed as such to the patient.[5] However, there are strong reasons to obtain HIV testing for a critically ill patient who is not improving and who may have an opportunistic infection that would require a radical change in treatment.[6] When the patient is unable to make a decision, a surrogate decision maker should be sought to give surrogate consent. If no surrogate can be identified, as in the case of Mr. G., it may be medically and ethically appropriate to obtain an HIV test without consent. If this occurs, the physicians need to explain reasons for obtaining the test when the patient recovers sufficiently to understand.

CONCLUSION

The AMA guidelines provide physicians with a solid framework with which to think through difficult situations of withholding information from patients. Our two cases add to this framework by posing a series of practical questions for clinicians who are disclosing information to patients. These questions shift the focus from *whether* to disclose information to *how to do so* in ways that minimize harms and maximize benefits to patients. By addressing these questions, physicians can continue to build on the trust and communication that is at the heart of any doctor-patient relationship.

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Comment on the CEJA Guidelines: Treating Patients Who Deny Reality

Edmund G. Howe

The guidelines regarding therapeutic privilege that were recently issued by the American Medical Association Council on Ethical and Judicial Affairs (CEJA) direct doctors to exercise their best clinical judgment. The guidelines state, "physicians should assess the amount of information a patient is capable of receiving at a given time. . . ." In doing this, the CEJA has affirmed physicians' traditional approach, which remains open to ethical challenge.

When a careprovider doesn't disclose information, patients may undergo many losses, the greatest of which may be to lose the opportunity to state what they want.[1] If careproviders disclose all information to all patients, however, this might cause some patients inordinate harm. If a patient is in a situation such that he or she must deny reality, and a careprovider provides too much information, it may overwhelm the patient's psychological defenses. In response, the patient may have a catastrophic and psychotic reaction, commit suicide, or leave treatment, as it appears Ms. E did in the case described by Nicole Sirotin and Bernard Lo in "The End of Therapeutic Privilege?" in this issue of *JCE*.[2]

The CEJA guidelines may, then, represent an optimal ethical compromise between extremes, but this still leaves careproviders with an extremely difficult clinical question: *When should we use this therapeutic privilege?* Ideally, to answer this question, careproviders should understand as much about denial as possible.[3] This is particularly important now, because the clinical significance of denial has recently changed radically. It had been viewed as being always pathological. Now, denial is viewed — in some cases — as being highly adaptive.[4] In some instances, for example, it may reflect that a patient is not allowing illness, even when it is fatal, to dictate the remaining quality of the patient's life. This "fighting spirit" may help the patient emotionally and socially.[5] It may also, in some cases, help a patient to live longer.[6]

This newly recognized difference in denial may be examined in considering scenes from two plays, Maxim Gorky's *The Lower Depths* and Eugene O'Neill's *The Iceman Cometh.* (In fact, O'Neill based his play on Gorky's). The main characters in the plays use denial to a great

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degree and rely on another character to help them in this — in a way as the characters in Samuel Beckett's play, *Waiting for Godot,* wait for Godot.[7] In Gorky's play, the character Satine (a Godot-like character from whom others derive hope and faith) says:

> I'm a convict, a murderer . . . granted. . . . [Roars with laughter]. . . . Man stands above hunger. . . . What's a man to be afraid of?[8]

In O'Neill's play, Hickey, a Godot-like character, says:

> It's always fair weather, when good fellows get together. . . . And another little drink won't do us any harm. . . . Bring on the rat poison.[9]

We might assume that these leading characters — and the characters who depend on them — are essentially the same in the two plays, especially as O'Neill based his play on Gorky's; in context, however, they are quite opposite. The character Satine in Gorky's play may offer the other characters a crucially important reason to "go on." As Gorky said of his own life,

> [Why do] I try to recall those vile abominations of that barbarous life in Russia. . . . [The] human power of goodness . . . awakens our indestructible hope that a brighter . . . life will be reborn.[10]

However, Stephen A. Black, in his biography of Eugene O'Neill, noted that writing *The Iceman Cometh*

> took O'Neill deep into his mother's . . . addiction, which had made it impossible for her to care for him during his childhood.[11]

While this inference regarding O'Neill is open to question, this possible contrast illustrates how denial may be beneficial in one context and harmful in another.

It appears that denial may be brought about consciously or unconsciously. Some patients report, for example, that denial is an active process, and that they produce it more or less intentionally to give themselves some more "time" (meaning time to absorb and adjust to highly distressing information).[12]

Other phenomena associated with denial seem to be "automatic and unmotivated."[13] How might this be explained? In an article, "The Management of Denial in Cancer Patients," H. Steven Greer, MD, FRC, offers an explanation regarding patients who have anorexia nervosa (AN): "Conditioning history and selective information processing can perpetuate symptoms independently of anorexics' will or intent."[14] Fortunately, whether denial is consciously or unconsciously motivated — or both — clinically, it doesn't make a difference. In either case, the approach is the same.

Sirotin and Lo present the basic guidelines in their commentary in this issue of *JCE.* As they point out, the core consideration is that confrontation may "increase resistance in most people."[15] Consequently, they urge careproviders who treat patients with denial to disclose new information slowly, to "titrate" it, if possible, to patients' apparent capacity to accept the information, and when necessary to disclose information only partially.

In addition, there are steps we can use to insure that patients' denial doesn't have a biological cause; for example, patients' denial may be caused by a brain tumor.[16] Careproviders should have accurate information on what other careproviders have told patients, to be sure that patients are actually denying information.[17] We can also discern whether a patient's denial interferes with obtaining optimal care. If it isn't, perhaps it may allow the patient to do better.[18]

Finally, careproviders should probably always consult with someone who has special expertise in mental health.[19] One reason that patients may acquire denial is that they unconsciously associate new, potentially threatening information with a previous painful experience that they — or someone they know — has had. If this is the case, a careprovider skilled in psychotherapy may be able to help patients see this connection. If patients can see the connection, they may also be able, as a result, to overcome their denial.[20]

Beyond these more-general principles, there are some additional approaches that careproviders may find useful, especially in more difficult cases.

"I'M NOT SURE I COULD LET YOU DIE"

As I suggested above, in some cases when patients' denial doesn't cause them to refuse treatment, it may be best to not intervene. Some patients report that they consciously deny to give themselves more time, as stated earlier. This suggests that in some cases patients may need additional time to give up their denial on their own. In a Japanese study just published, the careproviders on an in-patient service did not tell all of their patients that they had cancer. The authors explain that the patients went through stages of grief much like those Elizabeth Kubler-Ross described in her well-known research; however, the authors state that the patients who were not informed did better in their last days than the patients Kubler-Ross described, and they did better than the patients the authors used as a "control" group, who were informed.[21] While these are the findings of only one study, and its findings are extremely limited, it nonetheless may suggest a very important aspect of patients' reality: that they can "do best" if they can accept stressful new information at their own pace.

Notwithstanding this, however, it may be that, in all cases that may involve denial, careproviders should determine whether they may ultimately try to override a patient's wishes and treat them. If this might happen, careproviders should inform the patient ahead of time. The best example of this may be when a patient has AN and may deny that she or he is greatly underweight, which may ultimately result in the death of the patient. This type of denial is, in fact, pathognomonic of AN. As one careprovider states, these patients' "fiercely egosyntonic pursuit of symptoms distinguishes anorexics even from drug abusers who rival their reputation as unmotivated clients."[22] A critical difference between AN and many other medical conditions, such as cancer, is that AN is regarded as a psychiatric illness that legally may deprive patients of their capacity for competency. As this is the case, careproviders can try to hospitalize these patients against their will, and, when necessary, force-feed them.[23] Patients with other illnesses, such as cancer, may also deny that they are seriously ill and refuse treatment. Their careproviders may have no choice, however, but accept this.

When careproviders see a patient (such as a patient with AN) with whom they may intervene in this way, they should warn the patient, because that may be the only way to preserve the patient's trust. As K. Vitousek and S. Watson, leading experts on treating patients with AN noted, "Any hints of insincerity or duplicity can cause irreparable harm to the fragile alliance bridging the separate interests of therapist and client."[24] Such "fragile alliances" may be the only way that some patients may be able to overcome their denial. By telling the truth from the start, careproviders may have a hope of being able to help patients. One strategy for patients with AN may be to say, "I must tell you something before we proceed. You can die from not eating. I'm not sure if I could bear that emotionally. If you chose not to eat, I don't know what I would feel. I might feel that I must do whatever I can, legally, to try to prevent you from dying. Since you know this now, you might want to try to find another doctor."

When careproviders say this, based on what they feel — not on the law — it may increase their credibility with a patient, particularly because it is honest. It is true that none of us can predict with 100 percent accuracy how we will react in the future. By stating that they are uncertain, careproviders may avoid triggering oppositional tendencies in patients who are "primed" to resist: careproviders who tell a patient something like this are not saying *what* they *will* do; they have only said what they *could* do.

In my own practice, I took an approach somewhat like this with a patient who had chosen the day on which he would take his own life. The psychiatrist whom the patient had been seeing — for years — was to move overseas in a short time. The patient told his psychiatrist about his decision, and the day he chose. The

patient had been hospitalized and received electroconvulsive therapy (ECT) for severe and intractable depression many times. The psychiatrist believed she could try to hospitalize him involuntarily, and administer ECT against his will, but that this would make his prognosis worse in the long run. The patient indicated this was absolutely what he didn't want, and would regard this as a complete betrayal. He indicated that if the psychiatrist did this he would "get out" sooner or later, and then would certainly not see a careprovider, but would end his life.

The patient said he wanted to stop seeing the psychiatrist immediately, so that when the day came weeks later, he could end his life without hurting her quite as much. She knew she didn't want to hospitalize him against his will, but beyond this she didn't know what to do. She consulted me, and I met with the patient. I said that I would be willing to continue to meet with him, to see if he could feel better and/or better accept his life as it was. I said that he had to know that I couldn't guarantee that, as the date came nearer, I wouldn't try to do everything I could to try to save his life. I said, "I can't imagine seeing you one morning, knowing that you will go and kill yourself later on the same day." He agreed to continue to meet with me, and I have to admit that I became "unraveled" as the date came nearer; especially after a meeting less than a week before the date, when he called to tell me he lied when he said that he no longer planned to kill himself. Fortunately — in my view — the date passed and he still hasn't ended his life. He is trying, instead, to see if he can feel better.[25]

HOW WOULD YOU FEEL IF SOMEONE SAID, "I THINK YOU SHOULD GIVE UP YOUR CHILD"?

In many instances, careproviders will already have a relationship with a patient before a difficult diagnosis is made. In these cases, careproviders may ask the patient how much he or she would want to know once the diagnosis has been made. As Sirotin and Lo note, some patients may specifically say they don't want any information.

But when careproviders already know a patient's diagnosis, the dilemma is exponentially greater. Perhaps careproviders should not ask the patient what she or he thinks a hypothetical patient in the same situation might want (even though this is often advised). Asking this question in this way risks destroying the patient's trust — the patient may see through this and realize that the careprovider is asking the patient about himself or herself in a disguised way. The patient may conclude that if the careprovider is unwilling to be forthright, the careprovider may be less than honest with the patient and may not be able to work with the patient effectively.

To reach patients with denial, careproviders must first be able to truly empathize with them. As Vitousek and Watson suggest, "Clinicians need to acquire a frame of reference that helps them 'get' this condition before they can make effective use of . . . techniques for validating the experience of difficult clients."[26]

"Getting" a patient's frame of reference may not be as easy as it would seem. To imagine how a patient feels when her or his denial is challenged, Vitousek and Watson suggest trying to imagine how we would respond if a careprovider said to us, "After careful assessment of your family, I am convinced that it was a terrible mistake for you to have had your daughter. . . . Therefore, I have decided to take your daughter away."[27]

Once we have tried to imagine this, then we may be able to elicit patients' reasons for having and maintaining their denial — as well as they are able to provide a reason.

Once a patient provides reasons, careproviders can continue to help them by "validating" the reasons. In most cases this is not difficult. As Vitousek and Watson point out regarding patients with AN, for example, "After all, they do feel better when they lose weight, and they do feel worse when they gain."[28] Careproviders can acknowledge other reasons that patients may have for denial, including the desperation that patients may feel about changing when they don't want to change, or patients' fear of losing control in front of others whom they don't trust.[29]

Careproviders could consider praising patients for having courage — the courage to maintain their denial, notwithstanding the extreme pressure they may face from others. One might say, for instance, "It must be extraordinarily difficult for you to maintain this belief when you are under such pressure from others to give it up. What courage you must have. . . . I am not sure I could do this at all."[30]

If a careprovider can acknowledge a patient's reason for denial, they might be able to ask a patient if he or she would be willing to discuss the "pros and cons" of making a decision that would be consistent with the patient's denial. If the patient gives permission to do this, the careprovider can take the lead in asking helpful questions. For example, for a patient with AN, a careprovider could ask, "Would the significance of your body's shape change for you if you were stranded on a desert island?"[31]

Finally, careproviders might invite patients to consider changing their behavior on a wager, like Pascal. For example, patients may still choose to believe within themselves that they don't have a disease like cancer, but, at the same time, accept treatment regardless.[32] Careproviders can also introduce other reasons that patients might accept treatment; for example, if patients accept treatment — regardless of their own beliefs about illness — this may provide profound emotional relief for their family members and other loved ones.

In time, patients may decide, consciously or unconsciously, in response to these questions, that their denial — or at least the consequences of refusing treatment due to denial — isn't "worth it." If they don't make this decision, however, it is unlikely that they will ever give up their denial.

Given all of these considerations, patients' interpersonal interactions with their careprovider may be the best — perhaps only — way that they have to overcome denial. As their denial may have begun in response to interpersonal pressures, it may be through interpersonal relationships that their denial is best undone.[33]

Such "undoing" may occur as it did in this case. At 3 a.m., a patient, who was unable to sleep, began to talk with the nurse who was sitting by her side. After weeks in the hospital, still showing denial, the patient suddenly asked the nurse, "Do you think there's any chance that what all my doctors have been telling me might be true?"

NOTES

1. As D. Pirakitikulr and H.J. Bursztajn state, in "The Grand Inquisitor's Choice: Comment on the CEJA Report on Withholding Information from Patients," in this issue of *JCE,* the CEJA guidelines could be used by physicians as a Trojan horse to excuse failure to obtain informed consent. As Norman Quist noted, to give careproviders discretion keeps the door open for "backdoor paternalism." Communication with the author, November 2006.

2. M. Marzanski, "Would You like to Know What is Wrong with You? On Telling the Truth to Patients with Dementia," *Journal of Medical Ethics* 26, no. 2 (April 2000): 108-13.

3. See, generally, M.S. Vos and J.C. Haes, "Denial in Cancer Patients, an Exploratory Review," *Psych-Oncology* (25 July 2006), *www.interscience.wiley.com DOI: 10.1002/pon.1051.* This piece distinguishes four different kinds of denial and reviews all of the studies regarding each.

4. The concept of denial originated in psychoanalytic theory.

5. R. Goldbeck, "Denial in Physical Illness," *Journal of Psychosomatic Research* 43, no. 6 (1997): 575-93. For a provocative discussion of how information may make decision-making worse, see also R. De Vries and C. Elliot, "Why Disclosure?" *Journal of General Internal Medicine* 21, no. 9 (2006): 1003-4.

6. S. Greer, "The Management of Denial in Cancer Patients," *Oncology* 6, no. 12 (December 1992): 33-6, and D. Dudley et al., "Long-Term Adjustment, Prognosis and Death in Irreversible Diffuse Obstructive Pulmonary Syndrome," *Psychosomatic Medicine* 31 (1969): 310-25.

7. S. Beckett, *Waiting for Godot* (New York: Grove Press, 1982).

8. M. Gorky, *The Lower Depths,* trans. J. Covan (Mineola, N.Y.: Dover Publications, 2000), 61-2.

9. E. O'Neill, *The Iceman Cometh* (New York: Vintage Books, 1957), 76.

10. M. Gorky, *My Childhood,* trans. R. Wilks (London: Penguin Books, 1966), 217.

11. S.A. Black, *Eugene O'Neill* (Yale University Press, 1999), 424.

12. C. O'Callaghan, T. Powell, and J. Oyebode, "An Exploration of the Experience of Gaining Awareness of Deficit in People Who Have Suffered a Traumatic Brain Injury," *Neuropsychological Rehabilitation* 16, no. 5 (2006): 579-93, 591.

13. Greer, see note 6 above.

14. Ibid.

15. Ibid.

16. Goldbeck, see note 5 above, p. 586.

17. Ibid., 585-6.

18. Ibid.

19. Greer, see note 6 above.

20. Ibid., 36.

21. Y. Maeda et al., "Psychological Process from Hospitalization to Death among Uniformed Terminal Liver Cancer Patients in Japan," *BMC Palliative Care* 5, no. 6 (2006), *www.biomed central. com/1472-684X/5/6 doi: 10.1186/1472-684X-5-6.* "The informed patients of Kubler-Ross were not happy and were almost devoid of feelings at the 'acceptance' stage, . . . the uninformed patients in this study had peaceful feelings about accepting death," (p. 19).

22. K. Vitousek and S. Watson, "Enhancing Motivation for Change in Treatment-Resistant Eating Disorders," *Clinical Psychology Review* 18, no. 4 (1998): 391-420, at 393. See also C. MacDonald, "Treatment Resistance in Anorexia Nervosa and the Pervasiveness of Ethics in Clinical Decision Making, *Canadian Journal of Psychiatry* 47, no. 3 (1 April 2002): 267-70; Work Group on Eating Disorders, "Treatment of Patients with Eating Disorders," *American Journal of Psychiatry* 163, no. 7 (2 July 2006, supp.): 1-54.

23. M. Gans and W.B. Gunn, Jr., "End Stage Anorexia: Criteria for Competence to Refuse Treatment," *International Journal of Law and Psychiatry* 26 (2003): 677-95.

24. Vitousek and Watson, see note 22 above.

25. In light of this patient's profound, unremitting emotional suffering, others may feel that it is not fortunate that he survived past this date.

26. Vitousek and Watson, see note 22 above, p. 398.

27. Ibid., 394.

28. Vitousek and Watson, see note 22 above.

29. Ibid.

30. An example of the success of this approach is offered by psychiatrist Leston Havens. In regard to a patient with schizophrenia who had denial, Havens states, "[When I] admired him for clinging to [his ideals], . . . the bridge back to his mature self was put in place." L. Haven, *A Safe Place* (New York: Ballantine, 1989), 113.

31. Vitousek and Watson, see note 22 above.

32. J.A. Connor, *Pascal's Wager* (San Francisco: Harper, 2006), 200.

33. This is suggested by studies that report that persons may be more likely to show denial if they are married, and that they may be more likely to have denial if they have lung cancer. J. Levine and E. Zigler, "Denial and Self-Image in Stroke, Lung Cancer, and Heart Disease," *Journal of Consulting and Clinical Psychology* 43, no.6 (1975): 751-7. See also Vos and Haes, see note 3 above.

The finding regarding marital state may result from a need or desire to protect others; if patients' loved ones know the truth, they may experience extraordinarily emotional pain, and patients may experience pain each time they see others' pain in response to them. A.A. Reinders et al., "Detecting Fearful and Neutral Faces: Latency Differences in Amygdale-Hippocampal Junction," *Neuroimage* 33, no. 2 (1 November 2006): 805-14. Each time patients' pain is cued by discussion of their illness, it may make the pain more intense. More generally, talking about painful realities can increase patients' trauma. See R. Mayou, A. Ehlers, and M. Hobbs, "Psychological Debriefing for Road Traffic Accident Victims: Three-Year Follow-Up of a Randomized Controlled Trial," *British Journal of Psychiatry* 176 (2000): 589-93. This repeated stress may result in the pain becoming ever-present, rather than transient. J. Debiek and J. LeDoux, "Noradrenergic Signaling in the Amygdala Contributes to the Reconsolidation of Fear Memory," *Annals of the New York Academy of Sciences* 1071 (2006): 521-4; G.M. Morris et al., "Memory Reconsolidation: Sensitivity of Spatial Memory to Inhibition of Protein Synthesis in Dorsal Hippocampus during Encoding and Retrieval," *Neuron* 50 (4 May 2006): 479-89.

The latter finding (regarding lung cancer, smoking, and guilt), some suggest, may be caused by patients' feelings that contributed to acquiring cancer by smoking; and so they deny their illness, consciously or unconsciously, to assuage feelings of guilt.

When Patients Do Not Have a Proxy: A Procedure for Medical Decision Making When There Is No One to Speak for the Patient

Insoo Hyun, Cynthia Griggins, Margaret Weiss, Dorothy Robbins, Allyson Robichaud, and Barbara Daly

The case of Theresa ("Terri") Schiavo drew national attention to the problems that can arise when too many family members and others compete to speak on behalf of a decisionally incapable patient. Today, healthcare providers are more likely to encounter the opposite problem — namely, that of caring for a decisionally incapable patient when there are *no* family members or other surrogates to assist in the medical decision-making process. This challenge is made even more difficult when there is neither a written advance directive nor any other evidence of personal values that can help the medical staff employ a substituted-judgment standard for making decisions about treatment. Particularly problematic are situations in which treatment of a patient's disease may require a significant medical intervention for which consent is necessary, such as amputation, ventilator support for pneumonia, or the insertion of a percutaneous endoscopic gastrostomy (PEG) tube. What guidelines should medical staff follow when significant non-emergent medical decisions must be made on behalf of a decisionally incapable patient and there is not enough time, or it is not possible, to get judicial authorization for a court-appointed guardian?

Healthcare providers should tend to these circumstances very carefully, for the stakes are indeed high. On the one hand, some may feel

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pressure to employ all available treatments, fearing a charge of civil liability from a previously unknown relative who suddenly appears complaining that doctors did not do "everything possible." Others may decide to limit treatment, and choose instead to wait silently for the patient's condition to progress to an emergency, thereby obviating the need for someone to give informed consent for treatment. In either case, the potential for harming patients is great in terms of added suffering, illness, and indignity.

We encourage hospitals and their ethics committees to pay serious attention to this issue. According to a 2003 report by the American Bar Association Commission on Law and Aging, caring for patients who are incapacitated and alone is a critical and escalating issue.[1] Most of these patients come to hospitals from nursing homes and institutions for the developmentally disabled. Although the exact number of patients without proxies in the U.S. today is not known, it is likely to be considerable. For instance, by extrapolating from a 1991 study of average-sized nursing homes, one commentator has conservatively estimated that there are more than 60,000 seniors who fall into this category.[2] Furthermore, recent demographic data suggest that the population of incapacitated patients who lack surrogates in the U.S. is becoming ever more sizable and diverse. Between 2010 and 2030, the number of decisionally incapable patients who will lack surrogates is expected to rise dramatically in the U.S. due to the aging Baby Boomer generation, the expanding population of elderly with dementia, and the growing number of seniors who live on their own.[3]

In light of these trends, we believe hospitals should now begin to formulate their own institutional policies for the ethical treatment of decisionally incapable patients who lack a surrogate, especially those for whom a timely decision must be made regarding a significant non-emergent medical intervention. Such policies should provide a readily available and consistent approach, with procedures that are open to critique. Although a handful of legislative mechanisms and local practices exist to help guide the medical care of these patients, we believe these avenues include disadvantages that are serious enough to warrant a search for alternatives.

We will first describe current approaches and their attendant difficulties, then we will offer our own recommendations for hospital policy. We suggest that our model policy can provide a template for other hospitals to formulate their own policies, although some institutional variation in implementation may be necessary.

POTENTIAL APPROACHES

Presently there are two general approaches to caring for patients who do not have a proxy: one approach involves a single decision maker, the other uses a committee. Of these, the use of a single decision maker is more widespread. To date, 10 states have established statutory authorization for healthcare consent when no surrogate is available and when a full-fledged guardianship proceeding would be impractical.[4] Eight of these states have designated a single person to be the key decision maker, normally the attending physician or another employee of the hospital or institution where the patient resides.[5] In addition to these state statutes, some states will expedite judicial authorization for treatment or assign temporary guardians for medical treatment.[6] Intended to be far quicker than a normal guardianship proceeding, these judicial authorizations involve either a determination for medical treatment that is made by a judge or the designation of a temporary guardian whose role is limited to making a medical decision for a patient. Finally, it is worth acknowledging that in states where there are no legally codified mechanisms, or in situations when careproviders ignore or lack awareness of codified guidelines, it may be quite common for careproviders to "fly beneath the radar" by making their own treatment determinations or by obtaining a second physician's concurrence with their decisions.

While having a single decision maker may be expedient, we maintain that it is not the most

ethically ideal. First, if the designated decision maker is an employee of the patient's hospital or institution, a danger lurks that the patient's medical decisions could be (or could appear to be) compromised by a third-party's interests or by financial incentives. This is especially worrisome when there is no guarantee of an external review of a surrogate's decision mandated in the state statute. Second, medical decision making should not be solely a matter of medical expertise and judgment; rather, it should involve a complex blend of careful medical and ethical reflection. For this reason, having a sole decision maker is not as desirable as an approach that utilizes the careful ethical deliberations and perspectives of more than one person. Indeed, some designated decision makers — for example, some attending physicians — may be uncomfortable with their assigned roles and may prefer to have others involved in the decision-making process. Third, careproviders who choose to "fly below the radar" risk doing so without proper accountability and oversight, and might rely too heavily on their own biases. To summarize, using a single decision maker may not be ethically optimal due to possible conflicts of interest — real or perceived — and the missed benefits of having more than one deliberator involved in the decision-making process.

In contrast to having a single decision maker, the use of a committee might, by its very nature, avoid many of the difficulties just outlined. Unfortunately, the chief problem with this latter approach is that it is normally weighed down with practical difficulties. To illustrate, consider three versions in which committees are now utilized.

A few states have authorized external surrogate decision-making committees to make collective decisions for patients who are incapacitated and alone.[7] These committees are comprised of trained volunteers who focus primarily on caring for residents of institutions for the developmentally disabled. Some critics have doubted whether these kinds of committees can be adequately expanded to cover treatment decisions for all types of incapacitated patients.[8] Given the likely increase in the number of cases in the future as this population expands, it could be difficult to train and administratively manage an adequate pool of volunteers. A similar problem exists for localities that have public guardianship programs that are funded by the State or private organizations. These programs tend to be underfunded and understaffed.[9]

In light of these practical difficulties, one might suggest that a hospital ethics committee act as the primary participant in medical decision making for patients who do not have a proxy. Hospital ethics committees, however, are not authorized to make medical decisions. Furthermore, it is rarely feasible to assemble an ethics committee on short notice each time a significant treatment decision needs to be made for a patient, especially if the need for such decisions is frequent. While a hospital ethics committee may be useful to review controversial cases, it is an unwieldy instrument for use as the primary participant in making medical decisions for patients who lack a proxy.[10] Our conclusion is this: whether one is talking about state-authorized committees, public guardianship programs, or hospital ethics committees, the committee approach may be simply too overburdened, underfunded, and cumbersome to be of much practical use.

RECOMMENDED GUIDELINES

In our state of Ohio, as in most states, there are no established judicial mechanisms that address the problem of how best to represent the interests of patients who do not have proxies and, at the same time, facilitate medical decision making. Furthermore, in our county, it can take three to six weeks — or longer — to obtain a court-appointed guardian. As a result of these limitations, we developed, and propose here, a modified version of the committee approach to care for patients without proxies. This collaborative decision-making process is comprised of the following series of recommendations.

STEP 1

Members of the medical staff should contact the appropriate social worker and the ethics consultant on call when a non-emergent but significant medical decision must be made relatively soon for a patient who does not have a proxy.

STEP 2A

The ethics consultant and social worker must ensure that a thorough and exhaustive search for possible surrogates has been made. They will contact the referral source and research the patient's background to inform the medical team about the patient's life-style and personal value system, if known. If no family members or friends can be found, the social worker shall consider initiating proceedings to obtain a court-appointed guardian for future decisions regarding medical care and discharge plans.

STEP 2B

At the same time, the ethics consultant will convene a pre-established subcommittee of the hospital ethics committee. This subcommittee will be comprised of no fewer than two members of the hospital ethics committee (from a pool of several members) who are knowledgeable about the ethics of surrogate medical decision making and who are available for consultation on relatively short notice (less than 24 hours). Ideally, one member of the subcommittee should be a community member.

STEP 3

Having consulted with the social worker, the subcommittee will deliberate with the attending physician about the patient's treatment alternatives — including the choice of no treatment — and will reach a consensus about an ethically appropriate course of action. The process of deliberation shall focus on considerations of the patient's quality of life, personal preferences, if known, and medical prognosis, so that the resulting treatment recommendation is based on a best-interests standard of care.

STEP 4

If there is no clear consensus in step 3, the case will go immediately to the full hospital ethics committee. Together, the attending physician and the hospital ethics committee shall arrive at a consensus about an ethically appropriate course of action.

STEP 5

If there is no clear consensus in step 4, the case will be brought immediately to the attention of the chief medical officer. The chief medical officer shall make a recommendation for resolution of the situation after considering the views of the attending physician and members of the hospital ethics committee.

Because the patient is not known by those who will decide his or her care, the process of deliberation must focus on determining the best interests of the patient. A sound basis for decision making in such cases must consider a number of factors. As with all decisions in medicine, the probable benefits and burdens of the various alternative courses of treatment must be discussed. Burdens include not only pain and discomfort, but also loss or absence of pleasurable experiences, such as eating, walking, interacting with others, or living in a familiar and desired environment. Benefits might include improvement in quality of life or return to a previous quality; a decrease in pain, discomfort, or other symptoms; or an increase in function. Under a best-interests standard, surrogate decision makers must seek the highest benefit among the available alternatives on behalf of the patient.

Following an evaluation of the benefits and burdens, the subcommittee must ask if there is any basis for judging the patient's value system with regard to these benefits and burdens. For example, was this a patient who willingly sought medical care and followed through with restrictive or burdensome treatments? Or was the patient someone who rejected medications and restrictions? Did the patient seem to enjoy some activities of daily living such as eating,

interacting with others, or participating in activities? Or was the patient "a loner," who frequently voiced dissatisfaction with his or her quality of life?

Deliberations on the particular medical facts of the case are important, including the likelihood of success of each treatment. Careful review with the medical team is necessary. For example, if a PEG tube is being considered for a patient with advanced Alzheimer's disease, discussion must include a review of the research that has failed to show increased survival with artificial nutrition and hydration. It is especially important to discuss whether a proposed treatment may actually restore cognitive function to the patient.

If there is some information to suggest the patient's values or to hint at his or her wishes, then the deliberating group is obliged to take them into account. Obviously, any decision that is guided by the patient's definition of "the good" is to be preferred. If there is no indication at all of what the patient might want, then the subcommittee must rely on estimates of what the "average reasonable person" would consider to be a benefit or burden, in an attempt to treat the patient with respect. Determining this is, of course, difficult and is subject to individual bias. This is why decision making by one individual or solely by medical personnel is undesirable.

Our proposed alternative is a modification of a common ethics consultation method. Ethics consultation programs sometimes consist of individual consultants who operate in much the same way as standard medical consultants do. That is, requests are made to an ethics service, and the individual who is on call responds and provides case review, advice, and assistance. An alternative structure is for consultation to be provided by duos or trios of ethics consultants. The proposed procedure is more easily and quickly implemented than calling together a full committee, yet it still reduces the likelihood that a single consultant may provide a biased or idiosyncratic recommendation. Although bias can never be completely eliminated, a small group trained in ethics consultation, operating on a best-interests standard, that has no vested interest in the decision to be made, can offer reasoned deliberation, while it still allows the vital exchange of views. In considering the problem of patients who do not have a proxy, it is particularly important to make every attempt to avoid the tendency to analyze situations solely from the perspective of typical medical and ethics staff — White, educated, middle- or upper-class, professionally trained, with loyalties to the organization and to the healthcare system itself; hence our recommendation that a nonmedical person from outside the institution be included. Many ethics committees have community members who meet these criteria.

CASE EXEMPLARS

We instituted this procedure more than a year ago in our hospital, a large, academic, urban medical center. The procedure has been used more than a dozen times. We offer these two case illustrations of our policy in action.

CASE 1

Mr. T was a 68-year-old male who had been a resident in a nursing home. He had a history of diabetes and several strokes, which resulted in aphasia and serious cognitive deficits. He was admitted to the hospital with new mental status changes and a fever. At the hospital, Mr. T was diagnosed with pneumonia and a urinary tract infection, and was treated with antibiotics. A speech evaluation, done early in the patient's hospitalization, noted generally poor nutrition, as well as a risk of aspiration. Therefore a PEG tube was recommended by the attending physician. Mr. T was taken to surgery for insertion of the PEG tube, but the GI [gastrointestinal] consultant noted that no consent had been signed. Because it was obvious that Mr. T could not consent by himself, and no proxy was available, he was sent back to the floor. It was at that point that an ethics consult was called. (This was on day 15 of Mr. T's hospitalization.) Efforts were made by a social worker to find family or friends who could serve as a proxy decision maker for Mr. T; however, he had no one — his spouse was deceased and they had no children. There were no other relatives or friends known by the nursing home.

The ethics consultant called together the ethics subcommittee. Two community members and the ethics consult-

ant reviewed the patient's chart, including the medical team's and the consultant's recommendations. With the medical social worker, they also contacted the nursing home to learn more about Mr. T's history there and his quality of life.

They learned that Mr. T was extremely limited in his activities. He was not very verbal, and mostly watched TV. He enjoyed eating. He did not appear to be in any pain or to be suffering in any way. The subcommittee also interviewed Mr. T, who despite his limited ability to converse, communicated that he was hungry. He demonstrated that he could in fact feed himself. He also said that he liked the nursing home where he was residing and hoped to return there.

The subcommittee asked for another swallowing evaluation. Despite a small chance of aspiration while eating, the subcommittee weighed the benefits and burdens of inserting a PEG tube. They felt that eating was one of the very few pleasures that remained for Mr. T. They also felt that the benefits of a PEG tube in extending life or preventing aspiration in patients like Mr. T were not impressive. Therefore the subcommittee recommended that Mr. T not be given a PEG tube, but rather that he be allowed to eat. They also recommended that a DNR [do not resuscitate] order be put in place, and that Mr. T be discharged back to his nursing home. The medical team accepted this recommendation, and Mr. T was discharged.

CASE 2

Mr. A was a 30-year-old ex-convict with AIDS. He resided in a nursing home after having been transferred from a halfway house for convicts. Mr. A was admitted to the hospital with a fever, possible urinary tract infection, and pneumonia. Mr. A had been on active HAART [highly active antiretroviral treatment] and had relatively few opportunistic infections, but did suffer from AIDS dementia. Mr. A's infection was successfully treated with antibiotics. However, due to his poor nutritional status, a PEG tube was recommended by the hospital staff.

Mr. A had no family members. The nursing home had made efforts in the past to locate a relative, without success. Nor did he have any friends who came to visit him. His only visitors were staff from the halfway house. Because Mr. A lacked capacity to consent to the PEG and had no proxy, an ethics consult was requested by the hospital staff.

The ethics subcommittee (two community members and the ethics consultant) reviewed Mr. A's medical situation and spoke with his treating team. With the help of a medical social worker, they also contacted the nursing home and learned that although Mr. A had not been there for long, he seemed to be adjusting well.

The subcommittee considered several issues. Mr. A was a young man. He had been committed to HAART, suggesting that he wanted to extend his life. He had relatively few opportunistic infections, indicating that the medication was working and that it had the potential to extend life. The subcommittee knew that PEG tubes were highly effective in providing nutritional support in the short-term. The subcommittee felt that Mr. A should receive a PEG tube to help improve his nutritional status, and that in all likelihood it could then be removed. They recommended that the PEG be placed.

DISCUSSION

As these cases suggest, our ethics subcommittee approach is capable of producing timely yet carefully considered decisions based on the best interests of patients who do not have a proxy. Over the course of the past year, we have learned from our policy. First, we discovered that extensive research into a patient's background is absolutely essential and is frequently successful in finding a surrogate when there was thought to be none. In some instances, medical personnel and social workers, who are often overburdened, had not done a truly exhaustive search prior to calling for a consult. In more than half of the cases in which patients were initially thought to lack a proxy, our search did in fact identify a legal surrogate — an adult daughter who had moved, a sibling who had a different surname, or a relative in another state. In one of our cases, a close relative was found after the deliberation was completed, but prior to its implementation. This relative, who was ready and willing to participate in medical decision making for the patient, voiced his gratitude for the committee's efforts and agreed with their recommendations.

Second, we have found our policy to be relatively efficient and effective in generating clear recommendations that have been readily accepted by the medical staff at step 3. The subcommittee has been able to convene and offer recommendations within 24 hours, often less time than is typically spent questioning

whether, in fact, the patient lacks a proxy. Members of the medical staff have, in all cases thus far, expressed satisfaction and gratitude to the subcommittee for its assistance.

Third, both the medical and nonmedical members of the subcommittee have uniformly found the process of jointly reviewing the case, interacting with the patient to the extent possible, and engaging in the expanded dialogue that is necessary when discussing issues among persons with diverse backgrounds, to be extremely effective in identifying and evaluating the nuances of values and alternatives. In following our procedure, we have sought to avoid the outside pressures noted earlier, which may influence difficult treatment decisions by the medical staff and possibly deflect the best interests of the patient. By engaging in a careful consideration of the available alternatives in light of the patient's best interests, the subcommittee has been able to provide a respectful voice for those who have no one to speak for them. In so doing, we have realized, insofar as it is possible, the ethical principles meant to guide medical decision making.

The situation of patients who lack a proxy requires us, ultimately, to reconsider the requirements of the canonical principle of respect for persons. In everyday clinical situations, this principle is applied in the usual requirements of autonomy — informed consent, veracity, confidentiality. When confronted with a non-autonomous, ill individual, considerations of autonomy provide no direction, and we have had to consider the more foundational requirements of respect for persons.

Respect is a ubiquitous concept, having been applied to persons, non-autonomous human beings, fetuses, and nonhumans. It has come to connote the requirement to treat another with care, to recognize the inherent worth or value of the entity, including unique features and preferences, and to take care of or care for that valuable being.[11] We do not have access to the preferences of the proxy-less patient, and often have almost no information of those unique features that make the patient who he or she is. Thus, respect dictates that we be particularly cautious in relying on individual assessments of what is in the patient's "best interest." Requiring consultation from persons outside of the clinical team, from several consultants rather than one, and from at least one person who is not a hospital clinician is thus an attempt to respond to this aspect of the principle of respect.

This addresses the methodology of our guidelines, but the standards for decision making also must be grounded in the principle of respect. In meeting our obligation as health professionals and as ethics consultants to care for ill individuals, we are normally directed by beneficence and nonmaleficence, again relying on the patient's interpretation of his or her good. Absent this information, we rely on a shared understanding among the community of caregivers, again cognizant that we actually may be well outside a patient's community. Nevertheless, seeking consensus among members of a group who have a fiduciary responsibility, as members of an ethics committee, to act for the benefit of the patient, lends some validity to the judgments that are made. Absent permission or specification from the patient regarding what the patient constitutes as benefit, the principle of nonmaleficence must be given priority. Unlike beneficence, the duties of nonmaleficence entail an independent component of the knowledgeable professional's assessment of whether the harm of any proposed action is likely to be outweighed by the benefit. In other words, without informed consent, we lack permission to do acts we believe to be beneficial, but we retain the obligation to avoid doing what we believe to be harmful.[12] Clearly this prioritization of nonmaleficence does not escape subjective evaluation of benefits in our attempt to justify even small burdens of treatment, but we have relied on the relatively absolute principle of nonmaleficence in our practical reasoning about how to fulfill the obligation of respect.

There are still clear limitations of our process. No matter how carefully and thoughtfully the members of the subcommittee approach their task, they are still not actually representing the patient who is a stranger to them — the patient's true wishes are unknowable. Secondly,

despite efforts to enroll community members in the process, the subcommittee still tends to lack true diversity, and so they may not be able to approximate the wishes of those who are members of minority groups. Until more diverse members can be recruited, our decisions will not be truly pluralistic. Finally, although ethics committee members are usually immune from liability because of their membership on the committee, there is no law that protects them from possible lawsuit should some party decide to challenge a recommendation.

Although there is no case law in our state that establishes precedent or legal support for this process, we believe, given the silence of the law on this issue, that this process is a reasoned response to a growing social issue. With the increasing nursing home population in our country and the frequency with which elderly persons and the aging developmentally disabled will require surrogate decision making, we have an obligation to find appropriate ways to make decisions in the best interests of these vulnerable individuals. It is important to include assurances that health professionals or other individuals will not be able to unilaterally impose their own values onto patients who cannot speak for themselves. The use of an ethics subcommittee with nonmedical representation is one such assurance.

NOTES

1. N. Karp and E. Wood, *Incapacitated and Alone: Health Care Decision-Making for the Unbefriended Elderly* (Washington, D.C.: The American Bar Association Commission on Law and Aging, 2003).

2. M.R. Gillick, "Medical Decision-Making for the Unbefriended Nursing Home Resident," *Journal of Ethics, Law, and Aging* 1, no. 2 (1995): 87-92.

3. See note 1 above, p. 14.

4. Ibid., 19-22.

5. Ibid., 20-1.

6. Ibid., 29-31.

7. Ibid., 22-7.

8. T.E. Miller, C.H. Coleman, and A.M. Cugliari, "Treatment Decisions For Patients Without Surrogates: Rethinking Policies For a Vulnerable Population," *Journal of the American Geriatrics Society* 45 (1997): 369-74.

9. See note 1 above, pp. 27-9.

10. See note 2 above, p. 90.

11. M.T. Lysaught, "Respect: Or, How Respect for Persons Became Respect for Autonomy," *Journal of Medicine and Philosophy* 29, no. 6 (2004): 665-80.

12. V.A. Sharpe, "Why 'Do No Harm'?" *Theoretical Medicine* 18 (1997): 197-215.

Cases from the Harvard Ethics Consortium

A Mother's Death: The Story of "Margaret's" Children

Christine Mitchell

On Mother's Day, I sat down with "Margaret's" three children to talk about the way she died. They are all young adults — two daughters, "Mary" and "Martha," and a son, "Paul." We met in their home — the house these children had grown up in and taken care of their mother in for five years, which Paul bought so his mother could stay there. It had taken awhile for all of us to find a time to get together, and the irony that it turned out to be Mother's Day was not lost on any of us. "Somehow," one of her daughters said, "it seems right."

Their mother, Margaret, died at the age of 54 of severe progressive Alzheimer's disease that had left her speechless and increasingly agitated and defensive. When she started falling and becoming hard to control, her children brought her to the hospital. After a few admissions and discharges at a general hospital, she was admitted to McLean Hospital, a locked ward in a residential psychiatric facility where her behavior was less disturbing to others. Lots of medications and electroconvulsive therapy were tried over several months with little therapeutic benefit. Still, she was restless, yelling and pacing, and so difficult to feed that she dropped several dress sizes.

Her children believed she was suffering and thought she would never have wanted to be kept alive in this undignified state. They asked if she could be given something to relieve the restlessness, to keep her calm, and enable her to die peacefully. Some of her doctors and the children thought morphine was probably the best drug to use, but many nurses objected to medicating Margaret with opioids just to keep her calm. They were used to restless, inarticulate, emotionally labile patients like Margaret. They were not experienced in "end-of-life care" and were not accustomed to giving large enough doses of opioids to ensure a peaceful death. They asked for an ethics consult. There were differences of opinion about whether Margaret was actually suffering, about whether she

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should be medicated with morphine, about whether she was dying or even should be allowed to die sooner rather than later, and about whether a psychiatric hospital was the best place for her to die.

The children met with the ethics committee, talked with various staff, and even wrote a letter, requested by the ethicist, to explain their values, beliefs, and wishes for their mother's care and death. Finally, the children, the ethics committee, and the staff agreed that it would be best to transfer Margaret to a residential hospice, and she was evaluated for "terminal sedation" — giving morphine often enough and in large enough doses to keep a patient unconscious, and thereby pain-free, until she dies. In the end, terminal sedation was not needed, but enough morphine was used to keep Margaret calm. Ten days after she walked in the front door of the hospice, Margaret died peacefully with some of her family around her. In the following pages, you will read about Margaret and the ethical concerns that came up in deciding what constituted good care for her from the perspective of her physicians, Julieta Holman, MD, and David Brendel, MD, PhD, at McLean Hospital, and Rosemary Ryan, MD, at the hospice, and from the perspective of her children expressed in a conversation I had with them more than a year after Margaret's death.

Note: Throughout this case, the names of the patient and her children have been changed. Quotation marks have been used around these changed names at their first appearance in an article. No other information has been masked or changed in this case. The information presented in this case is used with the permission of the patient's children and the other parties involved.

The Ethics of Palliative Care in Psychiatry

Julieta Bleichmar Holman and David H. Brendel

We first met "Margaret" in the fourth month of her six-month admission to the geriatric psychiatry in-patient unit. Margaret was 54 years old and suffered from advanced dementia. At the time, few traces remained of the formerly demure, mild-mannered woman with sparkling blue eyes and gentle smile. Currently, she inhabited a state of almost constant agitation, with frequent fits of loud screaming and crying, which had prompted her three children to bring her for psychiatric admission.

The onset of Margaret's symptoms had been deceptively insidious. Six years prior, unexplained mistakes on the job had precipitated a leave of absence from work. Episodes of getting lost while driving had resulted in nonrenewal of her driver's license. As her cognitive status declined, her temporary work leave turned into a permanent retirement. Her son "Paul" moved in to live with her, and Paul and her two daughters, "Mary" and "Martha," alternated caring for her. Within a few years, Margaret had gone from living independently and working full-time as a highly valued registered nurse to being nonverbal, profoundly cognitively impaired, and exclusively reliant on her children for self-care.

Eventually, behavioral disturbances of dementia emerged. Shortly after 11 September 2001, she called 911, thinking terrorists were outside her window. She was often distraught for no discernible reason, and suffered bouts of uncontrollable yelling and agitated pacing, and was combative in response to care. One week prior to her index admission, she was admitted to a general hospital for management of unremitting agitation. An exhaustive work-up failed to elucidate potentially reversible causes of acute mental status changes. She spent much of that admission in restraints, and it was recommended that she be transferred to a geriatric psychiatry unit, with possible transition to a long-term care facility. At that point, her children opted to take her home, hoping that the more familiar home environment would decrease her level of distress. However, within a few hours, the children were forced to call 911 due to renewed escalation of behavioral dyscontrol.

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Margaret had no prior psychiatric history and an unremarkable medical history. She had been born and raised in Boston, as one of four children of an emotionally detached and occasionally physically abusive mother, and had been sexually abused by an uncle. She had married once, and had three children, but was eventually divorced. Her husband was in recovery from alcohol dependence. Later in life, he developed multiple sclerosis and was confined to a nursing home. Despite adverse circumstances, Margaret was described as a kind and generous person who bestowed unconditional love on her children. She had treasured her role as mother and nurse. She enjoyed arts and crafts, had many close friends, and was active in her religious community.

On admission, Margaret presented as a medium-built, middle-aged woman with short gray hair, looking considerably older than her chronological age. She sustained minimal eye contact and appeared sedated, in part from receiving intramuscular medications en route to the hospital. Her verbalizations were limited to soft moaning and whimpering. She was largely unable to participate in the intake process and was transferred to the geriatric in-patient unit.

Her six-month hospital course was marked by multiple treatment failures. Numerous medication trials were attempted with antipsychotics, mood stabilizers, antidepressants, and anxiolytics, without noticeable improvement. A course of nine electroconvulsive therapy treatments also proved ineffective. A review of her records revealed daily episodes of extreme agitation marked by unprovoked screaming (often lasting hours, and occasionally audible from outside the building), striking out at staff or other patients, and flinging herself against walls or onto the floor. Restraints were frequently required to ensure safety. In addition, Margaret underwent a profound physical decline, with a 60-pound weight loss due to poor oral intake. She had multiple internal medicine consults to rule out physical causes of pain, and, although her inability to communicate precluded certainty of the absence of physical pain, no findings on physical exams or laboratory studies appeared to indicate a physical cause for her distress.

Throughout her admission, Margaret's children remained actively involved in all aspects of her care. They closely monitored each twist and turn of her treatment course. With each medication change, they experienced renewed hopes that perhaps, this time, an intervention would be found to alleviate their mother's distress. However, despite momentary reprieves in her agitation, Margaret's improvement was never sustained. The children thus experienced the hospitalization as an emotional rollercoaster ride. Nonetheless, they deeply appreciated the treatment team's indefatigable efforts to help Margaret. The staff, in turn, grew unusually fond of Margaret's three remarkable children. Their aplomb and maturity in the face of their mother's plight inspired deep sympathy and admiration, particularly considering their relative young age at the onset of her illness (the youngest was in her late teens, and the oldest in his early twenties).

In light of Margaret's treatment-refractory symptoms and poor overall prognosis, several consultations with expert clinicians were sought for additional treatment recommendations. Suggestions were implemented, including one trial of dronabinol, based on a study demonstrating decreased agitation among patients with severe dementia.[1] Additionally, two consultants recommended a trial of opioid medications. While not customary, the use of opioids was shown in one study to be effective in reducing agitation and distress in patients with advanced dementia.[2] However, the use of narcotic pain medications for intractable behavioral disturbances of dementia remains controversial. Not surprisingly, members of the care team disagreed on the ethical validity of this treatment intervention. Some considered it unacceptable to assume the risk of falls, respiratory depression, and possible death associated with the use of these medications. Others felt it was morally wrong to withhold a treatment that might relieve Margaret's profound suffering. The disagreement became more pronounced, given the staff's level of attachment to Margaret and her

children. In light of the discomfort with this proposal, and the impasse it generated, an ethics consultation was requested with a member of the hospital's ethics committee.

In the fourth month of Margaret's stay, one of us (D.H.B.) performed an ethics consultation. After observing Margaret's behavior at several different times, and conducting discussions with her children and members of her multidisciplinary team, the following note was placed in her chart.

[Summary of history]

I personally examined [Margaret] [twice], at which times I observed her to be agitated and pacing in a restless and uncomfortable fashion. On both occasions she was groaning incoherently and appeared to have receptive and expressive aphasia. At the time of my second visit, she lunged toward me in the hallway and needed to be contained and redirected by a staff member on the unit. She appeared extremely uncomfortable and inconsolable. . . .

[Margaret's] three children have cared for her in their homes. Her divorced husband has multiple sclerosis and is not involved in her care. There are no other family members who are involved in decision making about her treatment. The children serve as her healthcare proxy and all three have been in basic agreement about important decisions related to her treatment. In light of her ongoing behavioral deterioration and poor prognosis, they have expressed a clear wish that she not be resuscitated if she goes into cardiac arrest and that no major medical interventions (including antibiotics or surgery) be implemented to treat acute illnesses. In addition, they have expressed a clear preference that she be treated with whatever medications are necessary to control her agitation and to reduce the emotional and physical discomfort that are associated with it. They understand that the use of sedating medications (such as opiates) could reduce her level of agitation but also put her at major risk of serious adverse medical events, such as extreme sedation, falls, respiratory depression, aspiration, and death . . . In a meeting with me and members of the treatment team . . . , all three children reiterated this wish and expressed a clear understanding of the risks inherent in using highly sedating medications to treat her extreme and treatment-refractory agitation, behavioral dyscontrol, and emotional distress.

During the meeting . . . , I explained to [Margaret's] three children that I would be available to facilitate discussions between them and the clinical team regarding the difficult treatment decisions that lie ahead. They understand that the use of medications to control her agitation might lead to medical complications that would be difficult to manage on a psychiatric unit. They understand the possibility that she might require hospice care if medications to treat her agitation caused serious medical consequences, such as respiratory depression. Because her agitation is so severe, her suffering is so great, and her prognosis is so grave, they believe strongly that sedating medications must be used at whatever dose is necessary to achieve the intended effect of reducing her agitation, even if the risk of using such medication is high and potentially fatal. They all believe strongly that this sort of intervention would be entirely consistent with their mother's previous wishes. They seek aggressive treatment of her agitation in order to enhance her quality of life but recognize that such treatment could have the unintended effect of causing medical complication and curtailing her life. From an ethical standpoint, the treatment team at this point would be justified in taking more definitive steps toward controlling her agitation and increasing her comfort. Because these steps are likely to include the use of highly sedating and risky medications, the team must assess carefully how to implement this treatment in a safe fashion. Arrangements for transfer to a medical unit, nursing home, or hospice may become necessary if safe and appropriate care cannot be provided on the geriatric psychiatry inpatient unit. . . . I would be happy to remain involved in the case if the treatment team and/or family members feel that ongoing ethics consultation could be helpful.

Following the ethics consult, the treatment team obtained a palliative care consultation. The palliative care specialist agreed that Margaret was suffering intensely and that management of her distress need not differ from the treatment of intractable pain in any other terminal illness. In other words, the use of opiates was not only justified, but in fact, indicated.

Six weeks after the initial start of the deliberations a decision was made to start Margaret on a trial of low-dose methadone. Almost immediately, Margaret exhibited a profound decrease in her level of agitation and distress. In addition, given Margaret's poor prognosis, the palliative care consultant suggested transfer to hospice. Approximately 10 days later, surrounded by family, and free of visible distress, Margaret died.

During her last week at hospice, Margaret had remained on low-dose opioids and had been sedated but not unable to breathe. She was noted to have a low-grade fever and difficulty clearing her oral secretions. The cause of her death was thought to be an aspiration pneumonia, although, as is consistent with hospice philosophy, no chest radiographs were obtained, and the fever was treated symptomatically with antipyretics but no antibiotics. Following her death, a post-mortem brain biopsy revealed dementia of the Alzheimer's type, rather than frontotemporal dementia, as had been previously thought.

Margaret's children recalled her last week as one of relative peace. One daughter described feeling "grateful" that her mother had died in the "cozy" and "welcoming" hospice environment. Despite undeniable sadness, the children also expressed feeling profound relief that their mother was no longer suffering. This reaction is consistent with empirical findings concerning the caregivers' responses to the death of their loved ones with dementia. In a landmark study of caregivers of dementia patients, more than two-thirds experienced their loved one's death as somewhat or very much a relief, and a vast majority believed somewhat or very much that the death had come as a relief to the patient.[3]

Interestingly, in the aftermath of Margaret's death, the children's reaction differed considerably from that of the psychiatric staff, who primarily experienced a sense of collective failure. This discrepancy seems understandable, given that transfer to hospice is not the usual aftercare plan for psychiatric patients. The general expectable outcome following a psychiatric admission is one of improved symptom control, with eventual discharge, usually within a matter of weeks, to a less restrictive setting. Yet, in part, this is precisely what makes Margaret's case noteworthy. Despite caring for countless patients with advanced dementia, psychiatric units and hospitals are not well-accustomed to confronting the complex ethical decisions surrounding end-of-life care.

In the psychiatric hospital, death is an uncommon event, usually the result of a suicide. Consequently, deaths are viewed as fundamental failures in the system and are associated with high levels of staff anxiety. This is partly due to the increased risk for malpractice litigation, but also to a sense that, unlike families of severely ill medical patients, families of psychiatric patients do not expect their loved ones to die in the psychiatric hospital. Psychiatric hospitals are meant to be places of safety, where patients go to be *prevented* from harming themselves. Hence, embracing a palliative care approach to advanced dementia, which could result in the death of a patient, appears anathema to the mission of psychiatry. Yet, the growing numbers of patients with dementia may cause psychiatric clinicians to be increasingly called upon to treat patients such as Margaret, who are unable to be cared for appropriately at home or in nursing homes.[4] In the future, psychiatric units and hospitals may become key settings in which to address the complex end-of-life decisions that confront patients with dementia and their families.

Obstacles to the adoption of palliative care for dementia include difficulties conceptualizing dementia as a terminal illness. In other terminal illnesses, such as cancer or end-stage AIDS, the doctrine of double-effect has gained broad acceptance. This principle argues that an otherwise unacceptable outcome — such as death — may be justifiably risked when it occurs secondary to the primary aim of reducing pain and suffering. Patients with dementia who suffer severe and intractable behavioral symptoms, not unlike metastatic cancer patients who have exhausted treatment options, constitute a cohort of patients in whom the magnitude of suffering renders the principle of double-effect ethically applicable.

Yet dementia straddles the fence between a terminal illness and a more gradually progressive but not necessarily fatal condition. Its unpredictable natural history, in which some individuals survive for decades, while others decline precipitously, makes predicting life expectancy challenging at best. This has practical ramifications, such as the under-representation of dementia patients in hospice programs, in

which a life expectancy of six months or less is a prerequisite for enrollment. Moreover, at the time of death, it is the medical event immediately preceding the death, rather than the underlying dementia, that is attributed as the ultimate cause of death. In Margaret's case, aspiration pneumonia, rather than end-stage dementia, was cited as the cause of death. While technically accurate, pneumonias and urinary tract infections are frequent complications of dementia, resulting from difficulty in swallowing and urinary incontinence. Thus, it could be argued that the underlying dementia, rather than the superimposed infection, was the ultimate cause of Margaret's death. This distancing of dementia from death contributes to the perception of dementia as a degenerative but not necessarily fatal illness, and may explain the discomfort with the acceptance of palliative care principles for select cases of advanced dementia.

The palliative care approach to dementia is further complicated by difficulties in establishing and implementing clear advanced directives for patients with dementia. Despite concerted efforts in recent years to encourage individuals to specify wishes for end-of-life care, most patients with terminal illnesses lack advance directives. For patients with cognitive impairment, timely establishment of such directives, at a point when the patient still has the capacity to make such decisions, is particularly important. Margaret's story underscores the need for continued public education on the importance of advance directives.

Yet, even when patients have established advance directives, inadvertent obstacles exist to the implementation of such directives. After Margaret's death, for instance, a legal document was found in her medical chart in which she explicitly delineated her wishes for end-of-life care. Margaret had signed this document three years prior, in the presence of her son, who was her healthcare proxy. Excerpts from this document read as follows.

> In the event that . . . I am no longer able to make cognitive decisions concerning myself, and . . . that there is no reasonable expectation of my recovery . . . to the extent that artificial and so-called "heroic" measures are required to keep me alive, I request that I be allowed to die a dignified death . . . that medication be liberally and mercifully administered to me to alleviate suffering even though this may hasten the moment of death, and that any action may be taken or withheld, as the case may be, so as not to unreasonably prolong my death nor destroy the dignity of my life. I . . . recognize the responsibility it places upon those of you who must carry out my request, but it is my belief that my right to die under these circumstances is just as precious as my right to live, and it is with the intention of relieving you of such responsibilities and of placing them upon myself that this statement is made.

It is notable how clearly and unambiguously this document embraces a treatment model that is entirely consistent with the palliative care approach that was ultimately adopted. Yet, it also is striking that, in and of itself, the existence of this document did not help to guide the treatment course, nor assuage concerns regarding the appropriateness of the use of narcotic medication. It underscores an unfortunate reality about advanced directives, which is that they often go unheeded. Promoting structured dialogue among families, clinicians, and patients regarding end-of-life wishes, before the onset of an acute crisis, would likely promote a more constructive use of advanced directives.

Margaret's advanced directive specified that medications should be used "liberally and mercifully" to "alleviate suffering." But at the heart of this case lies the question, What exactly is meant by *suffering*? Pain and suffering are intrinsically subjective phenomena. Historically, this has resulted in the undercognition and undertreatment of pain across healthcare settings. More recently, the adoption of "zero-tolerance" policies towards pain has resulted in an attempt to reverse this trend. Yet a distinction continues to be drawn between physical and psychological suffering, such that psychological or existential suffering is even more ill-defined, immeasurable, and unquantifiable than physical pain. For instance, we are far from understanding the complex processes that underlie the suffering experienced by someone with a crippling depression or intractable agitation of dementia.

The cognitively impaired patient's inability to communicate further precludes the clinician's understanding of the nature of the patient's pain and suffering. As a result, the notion of a "zero-tolerance" policy for existential suffering in patients with dementia is not met with the same acceptance as its counterpart for physical pain. In Margaret's case, her agitation and continual cries of distress suggested extreme pain and suffering. But the unknowable nature of this pain may have contributed to the discomfort with adopting a palliative care approach.

With the aging of the population and growing numbers of dementia patients, psychiatrists will increasingly be faced with similar problems in the coming years. Up to now, psychiatrists have been understandably reluctant to think of palliative care as a possibility for treatment-refractory agitation in dementia. But patients such as Margaret make it imperative that we entertain this option thoughtfully, that we heed relevant advance directives, and formulate treatment plans in collaboration with family members, clinical ethicists, palliative care clinicians, and specialists in related areas. Margaret and her three courageous children deserved no less.

NOTES

1. L. Volicer et al., "Effects of dronabinol on anorexia and disturbed behavior in patients with Alzheimer's disease," *International Journal of Geriatric Psychiatry* 12, no. 9 (1997): 913-9.

2. P.L. Manfredi et al., "Opioid treatment for agitation in patients with advanced dementia," *International Journal of Geriatric Psychiatry* 18, no. 8 (2003): 700-5.

3. R. Schulz et al., "End-of-Life Care and the Effects of Bereavement on Family Caregivers of Persons with Dementia," *New England Journal of Medicine* 349, no. 20 (2003): 1936-42.

4. M.M. Evers et al., "Palliative and Aggressive End-of-Life Care for Patients with Dementia," *Psychiatric Services* 53, no. 5 (2002): 609-13.

A Letter from the Children

24 August 2004

McLean Hospital
115 Mill Street
Belmont, MA 02478

To Whom It May Concern:

This letter is in reference to the care of "Margaret Smith," a loving and caring person. Margaret is a mother and a friend to all of her children. She was there during the tough times when no one else was around. She was there to relish the glory of the good times as well. It was the little things that mattered to Margaret. The smile of her kids, the crafts that she made, in general it was the pleasing of others that truly made her happy. Even in the state she is in now you get a tiny glimpse into her world. The loving hug or maybe even a kiss if you are lucky. Now Margaret, the person we call Mom, is taking on the toughest battle to date. The frustration began almost eight years ago when she lost her job as a Registered Nurse at the Faulkner Hospital. She spent a large majority of her life trying to make people comfortable through the care that she provided. We would like to reciprocate and give her the comfort care that she now deserves.

As this disease wore on our Mom began to change. We were now the ones caring for her. We prepared the dinners. We drove her places. We paid the bills. For what seems like a short period we cared for our Mom the best way we knew how. Now she is taken care of at McLean Hospital, where it seems that nothing works. The list of medications that have been tried seems endless and with that it appears the distress on our Mom's face grows. We can no longer ask her if she is feeling pain. The calling out, that everybody who comes into contact with her [experiences], has made it difficult for people to care for her. We often hear her voice as she was saying before things got so bad, "I do not want to go into a nursing home." Other times she would cry and tell us that she "did not want to be a burden to us." She didn't see the fact that she was our Mom and we would always do what was in her best interest. She deserves better than what has happened so far.

As we walk around the halls of SB2, we fight back the tears. We know that she will not get better and our major concern is that this is no quality of life. Our mother would not want to be this way. Recently it was told to us that she has become aggressive, an element that was never a part of the makeup of Margaret Smith.

We as a family feel that our mother should be sedated in the interest of providing her with the best comfort care possible. We do not want her resuscitated nor do we [want her to be] treated with antibiotics or surgeries for any illness. We say this because we feel this is no quality of life for our Mom.

Sincerely,
"Paul Smith" "Martha Smith" "Mary Smith"

Medicating "Margaret"

Coleen Reid

Nothing was going to be typical about this consult. I have seen only a few patients on inpatient psychiatric wards for palliative consultation. None of them were easy. So much of what I do is dependent on heart-to-heart conversations about what really matters most to people. When a person's faculties and judgment are impaired, the most powerful tools in my toolbox have been taken away. I also knew from my telephone conversation with the physician requesting this consult that it was out of the enormous distress of all concerned that I was being called in to help out in this very difficult situation.

It was a beautiful autumn evening, a Friday, in fact. I drove to the psychiatric hospital on my way home. I should have been forewarned when, misstepping off of the curb, I fell and twisted my ankle on the way into the hospital. Nevertheless, the pain I felt truly paled in comparison to the distress I was just about to witness.

Although I was a complete stranger to the staff, the nurses were very kind to me. They quickly found cold packs and a roll of gauze to tie around my swelling ankle. They also shared with me a packet of notes that the referring physician had left for me. It included the admission history and physical, consult notes from several esteemed psychiatrists, an ethics consult note, a living will, and most profoundly, a passionate and stirring letter by this patient's three children. Several of the night shift nurses were most helpful in sharing with me the extreme distress and conflict that had exploded amongst the staff regarding "Margaret's" care. Her continuous screaming had given way to outbursts of aggressive behavior, hitting, and biting. This had recently become less of a problem as she became increasingly less stable on her feet with frequent falls. She was also developing some periodic difficulty with swallowing. More of a problem were her frequent attempts to spit out oral medications the staff gave her. Although the patient's suffering was very serious, clearly she was not the only one suffering in this extreme and sad situation.

In a letter, Margaret's three children implored in unison that their compassionate mother be allowed comfort, peace, and dignity. They asked that she receive whatever medications would be necessary to keep her comfortable and sedated so that her remaining days of life might be quiet, without pain and suffering, and dignified.

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It doesn't get much clearer than that; and yet, I read on. To ease my distress about not having access to the patient's own thoughts, feelings, and goals, Margaret had even written a living will:

> To my Health Care Agent, my family, my physicians, my attorney, and to any medical facility in whose care I may be . . . I, [M.S.], hereby make the following declaration of my carefully deliberated wishes and intentions. . . . In the event that it has been reasonably determined that, on account of mental or physical illness or disability, I am no longer able to make cognitive decisions concerning myself, and if it is further determined, as described below, that there is no reasonable expectation of my recovery from such . . . disability, to the extent that artificial and so-called heroic measures are required to keep me alive, I request that I be allowed to die a dignified death, that I not be kept alive by such measures, that medication be liberally and mercifully administered to me to alleviate suffering even though this may hasten the moment of death, and that any action may be taken or withheld, as the case may be, so as not to unreasonably prolong my death or destroy the dignity of my life.

This witnessed declaration was authored exactly three years and three days before I met Margaret.

What still stands out these many months later was how inconsequential the pain in my ankle felt when I turned down the hall towards Margaret's room. A sitter occupied an old school chair in the middle of the hall outside her room. There Margaret was, lying flat on her back on a mat on the floor, eyes closed, moaning and groaning, bouncing her feet, crossed at the ankles, up and down on the floor. She had elbow pads because of contusions on both elbows, as well as a bruise on her forehead. Her room was otherwise stark and empty. Reluctant to scare her (or more honestly, reluctant to get bitten or hit), I just sat on the floor near her. I spoke softly. I slid a little closer. I reached over and touched her leg. She maintained a constant moan, and rhythmic bouncing of her outstretched legs, one foot on top of the other. Tears welled up as I leaned over to auscultate her chest and abdomen.

Reading through the notes and talking with the evening nurses, I learned that Margaret had lived this way for more than four months. Indeed, her current appearance sounded woefully improved from the constant screaming of the preceding months. Now, she was mostly moaning or pacing, repeatedly falling to the ground or bumping into walls. I heard the pain the nurses were also experiencing as they witnessed this profound and prolonged suffering, this loss of self, and the suffering of her three devoted adult children. Because of advanced dementia, Margaret had come to the in-patient psychiatric unit aphasic. They only knew Margaret through the constant presence, love, devotion, and stories of her three children. The nurses also told me of some recent vaginal bleeding Margaret had, explaining the diaper she wore. She'd also had several episodes of coughing and choking with meals and, less often, with meds.

Margaret had a most remarkable history. She had been diagnosed with dementia at the age of 46. She was now only 54. More recently, both her family and neurologists thought she might have Pick's disease. Her children had cared for her at home with 24-hour supervision for at least three years before this admission. Because of gradually worsening outbursts of uncontrollable screaming and crying, they brought her to an emergency room. A thorough radiologic, infectious, toxicological, metabolic, heavy-metal work-up unveiled no reversible cause for her worsening behaviors. She was transferred to this in-patient psychiatric hospital for help controlling her behavior. The children felt enormously guilty and remorseful that they were no longer able to manage their mother's care at their family home.

A methodical trial of the following therapies had failed to control Margaret's outbursts: olanzapine, perphenazine, clonazepine, quetiapine, haloperidol, chlorpromazine, fluphenazine, valproic acid, lithium carbonate, gabapentin, clonazepam, alprazolam, escitalopram, and mirtazepine. Lorazepam caused disinhibition and escalation of behavioral problems. Desperate to help, her physicians had tried several elec-

troconvulsive therapy treatments with no improvement. A one-week trial of a 25 mcg [microgram] fentanyl patch also had no effect.

Given her diagnosis of a progressive, life-limiting illness, Margaret's clearly expressed wishes written in advance, and the severity of her suffering, Margaret could very persuasively be considered a candidate for palliative sedation (sometimes referred to in the past as "terminal sedation"). However, it still was not clear to me that Margaret had received an adequate trial of pain medication to treat an underlying source of somatic pain that she was unable to tell us about. Why was she having irregular vaginal bleeding? Could she have an undiagnosed endometrial cancer? Cramping? She clearly would not tolerate a work-up, ultrasound, or exam. And even if something bad was found, what would we do differently? According to her own advance directive, she would not want treatment that would prolong her in this state, unless it was entirely pain relieving. There were several reasons that methadone was a very attractive choice: Margaret's nurses were reluctant to give her opioids and other as-needed pain medication, Margaret would spit out oral medication, and Margaret occasionally had trouble swallowing. Not only is it the least-expensive long-acting pain medication, it can be absorbed under the tongue, and comes in a concentrated liquid suspension. The analgesic effect lasts an average of 10 hours, and it can be given two to three times a day for around-the-clock analgesic coverage.

I paged the covering physician for confirmation that all possible reversible causes of delirium had been ruled out, and commented on the medical literature showing the benefit of pain management regimens for demented elders with behavioral issues who are simply unable to give a history of their experience of pain. I explained my reasoning for wanting to start Margaret on methadone 5 mg [milligrams] by mouth every eight hours. The physician at the other end of the phone took a deep breath, paused, and said he wasn't comfortable with this and that it could wait until Monday. In fact, to order any opioids, I had to get the covering house officer to come over to actually write the order. After calling the pharmacist to discuss what options he had on formulary, we had to settle on oxycodone 5 mg tablets every four hours scheduled and an additional 5 to 10 mg every four hours, as needed, for grimacing or increased screaming. I knew I couldn't rely on an as-needed order, as the nursing staff had clued me in that a number of the nurses would not use an opioid medication to treat Margaret's pain. Apparently, they felt (incorrectly, I might add) that this was tantamount to euthanizing her. We already knew that Margaret had tolerated a 25 mcg fentanyl patch, which is equivalent to somewhere between 50 and 90 mg of oral morphine. Nevertheless, perception is everything. Margaret did get a few doses of oxycodone, which has a duration of effect of about three to four hours. However, she ended up getting it irregularly. By the end of the following week, methadone was started, 5 mg every eight hours. She did not receive more than a couple extra doses for breakthrough pain. Though she did not show overwhelming changes the first week, Margaret seemed less agitated and slept more of the time. She was still awaking, attempting to ambulate, crying out occasionally, and taking in some, though less, oral intake.

At least 10 days later, I met with the children, the committed physician, the social worker, and the risk manager to assess the effect of the medication and to discuss the next options. I found Margaret still lying on the mat on the floor of her room, although she did appear slightly more peaceful. I met all three of her children, who joined in a wonderfully devoted and meaningful life review. They were able to express how this illness had impacted their own lives. They very lovingly supported one another in expressing their wish for her — that she be allowed a compassionate escape from agitation and suffering, and that a peaceful death free her from her current entrapment. They knew, as evidenced by many stories, that she would not choose to be sustained in her current state. We spoke about whether an underlying problem might be causing this behav-

ior. We talked about the principle of double-effect. They understood that euthanasia was not a legal option, but that carefully titrating medications to treat presumed pain was ethically appropriate, even if the medication brought sedation, potential aspiration, and even if it meant an increased risk of hastening death. We also discussed whether, once their mother's pain and behavioral outbursts were under control, they would want to take her home to care for her there with the support of a hospice team. Through abundant tears, they all admitted that they just did not have it in them to take on her care again. So we discussed the possibility of an in-patient or residential hospice, which would allow them to be with her as her family rather than as her constant caregivers. They were comforted by this idea.

I had already spoken with Rosemary Ryan, MD, the medical director of the nearest hospice, prior to the family and team meeting. I wanted to be sure that the hospice would take Margaret on before offering it as an option. I called the hospice from our meeting room, and it was determined that transfer to the residential hospice, Tippett Home, could happen the next day. Margaret's methadone was increased to 7.5 mg every eight hours, and she remained on that dose until her death. The family recalls that she walked into the hospice facility under her own steam, still moaning and crying at times. While at Tippett Home, Margaret received morphine when she needed it for breakthrough agitation or pain, along with lorazepam as needed. In speaking with Dr. Ryan and the children, I learned that Margaret's last days were peaceful. She died on the same regimen with her family at her side. They were grateful that hospice and medications were available for Margaret.

It is true that opioids can sedate, as do benzodiazepines. However, titration of pain medications or anxiolytics to effect pain relief, without rendering someone unconscious, does not constitute palliative sedation. Palliative sedation is the aggressive use of medications (typically intravenous lorazepam, midazolam, phenobarbitol, propafol, haloperidol) to achieve a comatose state in a patient with a terminal illness whose suffering cannot be ameliorated any other way. To do my work, I need to know I have a back-up plan when pain management efforts don't work. I want my patients to know that they won't be abandoned, that their symptoms can and will be addressed, and that, although we can't always control their illness, we can control their pain. When they are able, I want my patients to be able to choose. I don't usually start off talking about sedation as an option; it is a last resort in my repertoire. I need to try all the other ways I have to manage pain or other symptoms, allowing patients to remain involved and open to the miracles that may happen along the way. I have definitely seen many miracles in the course of my work, even though they do not necessarily have to do with cure.

For me to get up in the morning to meet the challenges of the day as a palliative care physician, and to go to bed at night without gnashing my teeth, I need to know that I can bring comfort to those who request comfort above all else. Margaret's regimen was used to achieve comfort *first.* The intent was to relieve her suffering. Her medications were titrated to that effect. This is not euthanasia, an action intentionally to taken to cause death. Although I am still uncertain about many things in Margaret's case — Did Margaret have somatic or psychic pain? How much was she suffering? How can we best support caregivers in these most stressful of circumstances? How could we have pre-empted this terrible scenario from unfolding the way it did? — I am certain that, in the end, Margaret and her family received the best possible, life-affirming care that medicine has to offer.

Palliative Care for "Margaret"

Rosemary Ryan

A few years ago, when I was the medical director of our hospice program, I was asked whether we would be able to provide palliative care for "Margaret." More specifically, if palliative sedation were needed to provide relief of her symptoms, could we — would we — be willing to provide it? When Coleen Reid, MD, a palliative care physician at Hospice of North Shore, contacted me, we discussed her review of the patient's records, assessment of the patient, options for treatment, symptoms, consultations from the medical, psychiatric, and ethics services, and her meeting with Margaret's professional caregivers and children.

Dr. Reid sent me the medical, psychiatric, and ethics consult notes, Margaret's advance directive, and a letter from her children [which appears in this issue of *JCE,* "A Letter from the Children"]. I reviewed Dr. Reid's recommendations and notes on Margaret's initial response to treatment with narcotics. Based on that information, I agreed that we would care for Margaret at Tippett Home — a 10-bed former mansion with homey common rooms, private patients' rooms, and 24-hour nursing and assistant staff on-site, dedicated to providing care and support for patients and families, along with a team of other staff, to help when needed.

Palliative care refers to whole-person care for patients whose diseases are not responsive to curative treatments. It is provided by an interdisciplinary team (IDT), includes very aggressive measures to control pain and other distressing symptoms, and can be provided in combination with treatments to control the progression of the disease or to facilitate remission.

Hospice is a program that provides coordinated comprehensive palliative care to patients who are terminally ill — and to their families — through an IDT who address clinical symptoms and psychosocial and spiritual needs.[1] Typically, hospice provides comprehensive care to patients with terminal illnesses. In the United States, the criteria for hospice care that has been stipulated by Medicare (and in Massachusetts by Medicaid and most private insurers) include the following:

- Having a terminal diagnosis,
- Having a prognosis of six months or less if the illness takes its usual course, and

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- Selection of hospice care by the patient or surrogate.

Palliative care and *hospice,* even though occasionally confused, are commonly used and are generally well understood.

Palliative sedation (PS), on the other hand, is not common and not well understood. PS involves treating the patient's distress by inducing as deep a level of sedation as necessary, with the sole intent of relieving refractory symptoms. It stands in contrast to the usual goals of palliative care, in which every effort is made to preserve consciousness while controlling pain, anxiety, agitation, the experience of breathlessness, existential suffering, and the like. PS may be defined and clinically characterized as the primary intention of deliberately inducing a temporary or permanent light-to-deep sleep, but not deliberately causing death, in patients with terminal illness and specific refractory symptoms.[2] While PS still requires a consistent definition and well-designed research, and is not infrequently confused with assisted suicide or with euthanasia, experience is demonstrating that PS can offer an important option for a more comfortable and dignified death for some patients. Within hospice it is increasingly recognized as a valuable palliative intervention, although it is used rarely — and with great care.

Our hospice program, acknowledging the occasional need to offer the choice of decreased consciousness to relieve significant refractory symptoms, developed a policy and procedure for PS with help from the Ethics Committee, Professional Advisory Committee, Board of Directors, and an attorney. Education about PS was provided for IDT staff, hospice residence staff, and volunteers. Our policy and procedure provides definitions of PS and refractory symptoms and also defines the purpose and intent of PS. A decision to use PS requires the following:

1. Review by the hospice medical director and vice president for hospice.
2. A do-not-resuscitate order and designated healthcare agent.
3. An option for psychiatric consultation at the discretion of the attending physician.
4. A meeting of the patient and family with the hospice medical director, appropriate members of the IDT, and, if possible, the attending physician for full discussion and consent.
5. The agreement of the attending physician.

We have a protocol for administration of the sedating agent (usually not a narcotic) and references for the sedating agents that are most commonly used.

PS is rarely used in the hospice programs with which I am familiar. Within the past year I have met with six patients in family meetings to describe the option of PS (out of the approximately 1,300 patients who received care during this time in the two programs for which I am medical director). All were relieved to know that PS would be possible if needed. In only one case have we resorted to PS when symptoms became unbearable. We didn't know whether Margaret would need it.

First, we needed to consider whether Margaret's end-stage dementia was a terminal illness. According to U.S. statistics for the most recent years, more than 50 percent of patients who receive hospice care now have end-stage system diseases with non-cancer diagnoses. Patients with dementia are well represented in this group. As hospice experience has increased, the National Hospice and Palliative Care Organization has developed guidelines for determining prognoses for non-cancer diseases. Combined Medicare and Medicaid services have adapted these guidelines to provide similar guidelines for local coverage determinations.

The guidelines for dementia refer to *primary, chronic, and progressive* cognitive impairment. Patients with very advanced dementia may live for a long time — years — depending on whether they have comprehensive care and other minor medical problems). Indicators of six-month mortality for advanced dementia include:

1. Functional decline, indicated by an inability to be independent in activities of daily living such as ambulating, dressing, bathing, toileting, and an inability to speak or communicate meaningfully.

2. The presence of medical complications, such as aspiration pneumonia or other significant infections, difficulty swallowing, or refusing to eat resulting in insufficient intake to sustain life, with a patient's or a surrogate's decision not to have tube feedings or intravenous nutrition provided medically. An unintentional weight loss of more than 10 percent in six months is considered an indicator for the likelihood of death within six months.[3]

Margaret's dementia was somewhat atypical in its early onset, frontotemporal symptoms, and marked agitation. Nevertheless, it had progressed to a very advanced stage, despite extensive work-up and efforts to reverse and/or treat its manifestations. Margaret's nutritional status had declined, and she had lost about 65 pounds because of her agitation and difficulty eating, either by herself or when fed. She weighed 132 pounds when she came to hospice. Her written directives for care, and the representations of her children (including her designated healthcare agent) regarding their understanding of her wishes, were clear that Margaret did not want medical nutrition and hydration even though she had lost considerable weight because of her diminished oral intake. Inadequate oral intake is common in end-stage dementia, though patients who are calm and willing can often be fed fairly adequately for a long time if their caregivers are persistent and patient. With Margaret's aggressive agitation, I assume that it was difficult or impossible for staff to supplement what she was able to eat on her own. There is increasing clinical evidence that, for patients with severe dementia, the benefits of tube feeding do not outweigh the burdens.[4]

So Margaret clearly met the guidelines for hospice care. The primary goal in our plan of care for Margaret was relief of her distress, whatever the cause. After several unsuccessful trials of medications primarily intended to control her agitation, her physicians at the psychiatric facility determined that a trial of opioids should be attempted, supplemented by medications to further relieve restlessness and other symptoms. At this point it might be of academic interest, but not necessarily helpful, to make a distinction between pain due to *physical causes,* pain due to *existential suffering,* and distress due to *other causes.* In any event, if the opioids would provide relief, they were clearly indicated. If Margaret could be calmed enough to accept care, we could help her with personal hygiene and feeding. The risk of aspiration while eating and drinking and the possibility of falling would remain, although standard precautions could be taken to reduce them.

Another important goal was support for Margaret's children. These young adults had cared for their mother for several years at home and had remained very involved through Margaret's long hospitalization. For some time she had not known them. Margaret was divorced from their father, who was in a nursing home with a degenerative chronic illness. The children were already coping with significant losses. The involvement of members of our team might be helpful to them — a social worker, a pastoral care coordinator, a bereavement coordinator, and a volunteer coordinator. Since Margaret was no longer able to participate in decision making, although she had prepared directives three years prior when she must have experienced earlier stages of cognitive loss and perhaps anticipated to some extent her eventual impairment, the burden of making ethical choices for her would fall upon her children, especially her son, whom she had appointed as her healthcare agent. Fortunately, Margaret's written preference for non-aggressive treatment, no feeding tube, and care focused on comfort was clear.

So Margaret left the geri-psych ward and came to Tippett Home. According to her transfer and admission records, she was alert, disoriented, confused, and unable to communicate. She did not appear to be in pain, but was anxious and agitated. Occasionally she vocalized with loud screeching, and attempted to walk. Due to recent falls, she was bruised on both knees. She required total care and was incontinent. There was an order in her chart not to do

cardiopulmonary resuscitation if her breathing or heart stopped. On the Karnofsky Performance Status Scale (a standard measure of function) she scored 30 percent (severely disabled although death not imminent). Described as having very poor po [oral] intake, she was able to drink some fluids and take a high-calorie dietary supplement. Her psychosocial and spiritual needs were assessed, and a priest, who was a friend of the family, visited Margaret and performed the Sacrament of the Sick.

Upon admission, Margaret's main medication was methadone 5 milligrams [mg] to be given by mouth at 9 a.m., 1 p.m., and 9 p.m. for agitation. She could also be given any of the following medications if she needed them: olanzapine (commercially named Zyprexa or Zydis), an orally disintegrating tablet, 5 mg every six hours as needed for agitation; lorazepam (Ativan), 1 mg by mouth under the tongue every six hours as needed for agitation; haloperidol (Haldol), 1 mg by mouth under the tongue every four to six hours as needed for agitation; acetaminophen (Tylenol), 650 mg by rectal suppository every four hours as needed for fever; hyoscyamine (Levsin), 0.125 mg by mouth under the tongue every four hours as needed for secretions and airway congestion; scopolamine (Transderm Scop), one to four transdermal patches every 72 hours as needed for airway congestion. In addition, she received laxatives because the medications to treat agitation tend to slow down bowel activity.

During most of her time at Tippett Home, Margaret was in bed and unresponsive, her condition very poor. She was weak and had significant congestion, which was treated with hyoscyamine four times a day for the first three days — then none. Aside from occasional sips, she took very little orally. One or more of her children were with Margaret day and night, often with several other family members visiting. The hospice chaplain offered her supportive presence, encouragement, and a blessing for spiritual comfort. The social worker noted that the children seemed ready for their mother's death after her prolonged illness, and that she had been a strong model for them before her illness. Because of Margaret's young age, her children were young adults and would be at higher risk for severe bereavement, although this seemed to be offset by the close supportiveness of the children and family.

During the first three days, Margaret had recurring fevers (100.6° Fahrenheit). Her attending physician visited and thought the most likely cause was aspiration pneumonia. Margaret was given acetaminophen three times on the second and third day of her stay, with good effect. It was needed only once on days four and five. On the second day, Margaret had an episode of inconsolable screaming and occasionally had lesser degrees of agitated behavior. Lorazepam was given three times on days two and three, usually with apparent relief. Haloperidol was given once on days two and three only.

Margaret's nurse noted increasing restlessness at night, possibly secondary to pain. This was discussed with the attending physician who ordered an increase in the frequency of methadone to every six hours, and morphine (Roxanol), 5 mg to 10 mg under her tongue every three to four hours when she needed it for breakthrough pain. From this time on, Margaret was given olanzapine every six hours and lorazepam every four to six hours fairly regularly, which calmed her episodes of agitation.

On the third day, Margaret's care was discussed at the weekly meeting of our IDT. They noted Margaret's increased agitation that day, the changes in her medication orders, and the likelihood that she was developing aspiration pneumonia. Since diagnostic procedures would not provide more comfort or quality of life, palliative measures were continued to control the fever and to provide as much comfort as possible without a medical investigation into the cause of her fever.

I visited Margaret in the residence on day four. She appeared to be comfortable in bed, her eyes open but not seeming to connect with those in the room. One of her daughters sat beside her, gently patting or holding Margaret's hand, while enjoying conversation with a cousin, the cousin's young child, an aunt, and one or two

other extended family members. They were very grateful for the homelike setting and greatly relieved that Margaret seemed to be peaceful most of the time. Their reminiscing was delightfully upbeat. While I was present, Margaret received some medications, coughing a bit and becoming agitated with unintelligible moaning for about five minutes until she again settled into what seemed a restful state. I had the impression that Margaret had some deep sense within her of the presence of those she knew — her family agreed. Although I knew that might be wishful thinking, it seemed a welcome comfort for her family members. They were aware that the end was near and did not want her to suffer any more.

From day four, Margaret declined more quickly, with increasing spells when she didn't breathe, choked when taking medications, and had congestion in her airway. Her final week was marked by periods of seeming to be comfortable, sometimes arousable, mostly unresponsive, interspersed with occasional episodes of agitation treated with lorazepam and olanzapine. Her condition precluded being able to take more than occasional fluids. Advanced dementia and minimal nutrition certainly contributed to her debilitated state. Medications that provided relief from episodes of agitation probably contributed to her decreasing ability to swallow and to handle secretions. It was not necessary to resort to PS to relieve Margaret's symptoms.

On the sixth day, one dose of Roxanol 5 mg was given. Later that day, Margaret died peacefully with her son, aunt, and uncle at her bedside. Her children expressed relief that their mother was comfortable in her last days. They continued to be included in bereavement support by hospice staff through the year following Margaret's death.

Margaret's young age and prolonged severe behavioral disturbance were unique features in an otherwise quite typical case of far-advanced dementia. The hospice team and staff were happy to provide comfort and support to her and her family during the final days of Margaret's untimely dying.

NOTES

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2. P. Rousseau, "Palliative Sedation in the Management of Refractory Symptoms," *Journal of Supportive Oncology* (March/April 2004): 181-6.

3. *Medical Guidelines for Determining Prognosis in Selected Non-Cancer Diseases,* 2nd ed. (Arlington, Va.: Medical Guidelines Task Force, Standards and Accreditation Committee, the National Hospice Organization, now the National Hospice and Palliative Care Organization, 1996), 12-3; C. Wolfson et al., "A reevaluation of the duration of survival after the onset of dementia," *New England Journal of Medicine* 344, no. 15 (2001): 1111-6.

4. M. Gillick, "Rethinking the role of tube feeding in patients with advanced dementia," *New England Journal of Medicine* 342, no. 3 (2000): 206-10; T. Finucane et al., "Tube feeding in patients with advanced dementia: A review of the evidence," *Journal of the American Medical Association* 282, no. 14 (1999): 1365-70; R. McCann, "Lack of evidence about tube feeding — food for thought," *Journal of the American Medical Association* 282, no. 14 (1999): 1380-1.

"Margaret's" Children Remember

Interview by Christine Mitchell

Christine: I never met your Mom. What was she like as a person, before she was sick?

"Paul": She was the person that would do anything for you. She'd give you the shirt off her back. If she had five bucks in her pocket, she'd give it to you. Even when she first got sick, she didn't tell us, you know. She would say, "I don't want to be a burden to you guys."

"Mary": She was a nurse. I think it was almost two years that she kept the illness from us.

Christine: How did you figure out that something was wrong?

"Martha": Actually, she lost her job. I guess she started messing up at the hospital, and they told her, "Maybe you should take some time off work." And there was a lot going on. I was just graduating from high school. Paul was just graduating from college, and my parents had just been divorced. It was kind of a mess. So they [at work] said, "Maybe you're stressed out; just take some time off work." I remember the day that they told her. She was standing in this living room, crying.

Mary: That's when she started going to the doctor, unbeknownst to us.

Paul: She was 48.

Mary: At that point she could still talk, but all she would say about it was, "I just want to get better so I can go back to work." She loved being a nurse. It was the right job for her. And I think she really wanted to believe that she would get better and go back. But I also think she knew deep down inside what was going on with her, because she was in the medical field.

Martha: She . . . her handwriting, she'd write stuff and she'd skip words, or her sentences weren't complete. She was also working two jobs.

Mary: Yeah, our parents had gotten divorced and she was "it". It almost made sense that she'd be overtired

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and maybe just not functioning properly. So I didn't really think . . .

Paul: Then she had a brain biopsy.

Martha: When the result came back, we were all upset. We all had a hard time with it because we had been really convinced that it wasn't Alzheimer's disease. It's scary because they say it's such an awful disease. And no one seemed to know why she kept getting worse, so fast.

Paul: I'd be on the internet for hours, till three in the morning, trying to figure out different ways to attack it. I had power of attorney at the time. We would bring stuff to the doctors and ask, and challenge them: "What new medicine can we use because the stuff we're doing is not working?" He was like, "Well, we can try that."

Mary: I was in college when it started getting real bad. But before that, she would never tell us when she had a doctor's appointment. She would walk from here to the Brigham and Women's Hospital [about five miles] just so she wouldn't have to burden us with having to drive her, because there came a point when it was clear to us that she shouldn't drive anymore.

Martha: Yeah. I remember one night, [Mary], me, and Mom went out to dinner. It was fall, winter maybe, so it was dark out early. Remember? We went to Old Country Buffet. She really wanted to go to Old Country Buffet. And we're driving down Route 1 and I'm sitting in the front seat, praying because, like you said, her reaction time was just not good. I remember saying "Do you want me to drive, do you want me to drive?" And she was just frustrated with herself, and she was just like, "No," you know, really angry almost. And shortly after that she stopped driving.

Christine: When you got power of attorney, was it for financial stuff or for healthcare decisions?

Paul: It was everything. I was her healthcare proxy.

Christine: When you talked to her about healthcare decisions, did she say anything about what she would want or not want?

Paul: One of the things that she did not want was to go into a nursing home. She didn't want to be the old lady in the nursing home.

Christine: Was she specific about anything else?

Mary: Being a nurse, you know, she's seen people, and she'd say, "That's no life; that's no way to live your life."

Paul: Yeah. Like Alzheimer's. I would not want that to be me. Just seeing my mother go through that. That's no way to live.

Christine: What was it like?

Paul: I almost think that the first day, when she went into McLean [a private psychiatric hospital affiliated with Harvard Medical School], was worse than when she passed away.

Martha: Yeah, I think so.

Mary: I mean, we had to let go.

Paul: We had no more control. We knew she wasn't coming home.

Mary: We were all in our twenties, and we had all pretty much put our lives on hold for five years to take care of her.

Paul: I bought this house at 24. At that point I didn't really want to buy it. I was two years out of college and like, you know, I was trying to have some fun. But the best thing for her was to make sure that she stays here as long as possible.

Christine: So much for going out drinking with the guys.

Paul: Yeah, that didn't happen.

Mary: There was a point when we were all living here. It was [Paul] and his wife, who was his girlfriend at the

time. And I was home from college. I graduated. [Martha] was here with her baby, and my mother.

Martha: And we were all living here at the same time. It was such a nightmare.

Christine: Did your mother like it? Or was it too much stimulation?

Martha: I think she liked having us all around. I don't think we liked it.

Mary: Yeah, it was very stressful. I think maybe we didn't realize how far along her disease was. The day that we initially brought her to Brigham & Women's Hospital I was taking care of her during the day while they were at work. I was convinced that she just wasn't feeling well, because her behavior had changed.

Martha: She couldn't talk.

Mary: Right. She couldn't talk. She could only say the word "two" in a high-pitched, chant-like way. And she would get really loud. That's just how she communicated; like if she wanted something, she'd say "two-two-two-two." Or, if one of us would leave and she didn't want us to go, she'd stand at the door and scream "two" over and over again.

Christine: What happened when you brought her to the Brigham & Women's Hospital?

Martha: When we went to her appointment, they said, "She has two years left." And we were, like, "What?" We were totally in denial about it. "Two? Come on, she's healthy, you know." But also she was really violent. I think they put her on Ativan, and admitted her.

Paul: Yeah, they restrained her.

Martha: Because she wouldn't sit still. They had to heavily, heavily medicate her. And she was strapped down to the bed. It was horrible. We thought, "Well, she just wants to go home. So we decided. "Let's just take her home." They medicated her, and we got her in the car and brought her home, and she took a nap. And then —

Mary: All hell broke loose.

Paul: Yeah, she was pretty violent — punching us. We got her calmed down, because we were used to having to calm her down anyway. Sometimes we'd have to actually lay in bed with her, or just sit there — I guess so she knew someone was there — and then she'd fall asleep. So that's what I did. I sat with her and then she fell asleep again. But when she got up, she started falling down. And then she tried to hit everybody that was in her way, so we finally had to call an ambulance for her. And that's when they put her in McLean Hospital [a psychiatric facility].

Martha: Before when she was sick, she was never violent, never. She hardly ever yelled at us.

Christine: So when you brought her to McLean, it was unexpected?

Mary: Well, yeah. Well no. . . .

Martha: They [the ambulance] took her back to the Brigham first.

Mary: What happened was the doctors at Brigham kept telling us all kinds of different scenarios and, for some reason, we met this young doctor.

Martha: He was an OB/GYN [a specialist in obstetrics and gynecology].

Paul: Yeah, he was an OB/GYN intern or something.

Christine: In the emergency room?

Paul: Yeah.

Mary: And he really pushed us to see that something's really wrong here.

Martha: His father was a neurologist.

Paul: Somehow he got her into McLean.

Christine: So when she went to McLean, what did you think?

Mary: Well, the day she went in was very emotional for all of us. It was worse than when she passed away, because

we knew that she wouldn't come home. And we had all rearranged our lives and put a lot of things on hold. Our lives revolved around her. For the first week I sat on the couch harassing my brother [Paul] at work, saying, "What am I going to do with myself? You know, my days were spent taking care of Mother."

Martha: She was more work than a baby. It was just an empty, lost feeling, as if she had died.

Paul: They [the staff at McLean Hospital] were really good. We were going every day [to visit], and they said, "You can't come every day." I'm like, "We're coming every day." And they'd say, "You're going to drive yourselves crazy." And I was like, "No, I don't think so." Then, you know, gradually, slowly, we were all right. They said, "For five years, you guys took care of her. Take a little breather here; we can handle it, you know."

Christine: Did she recognize you still when you visited?

Paul: At the beginning she did. Then, not so much.

Mary: But she would definitely look happy when we saw her. You know, her "two" would get higher pitched and faster. I mean, she always seemed excited to see us; but I don't know if it was because she knew us or just because we looked like a friendly face.

Christine: Did she ever come home again?

Paul: We brought her home for one day. We had a cookout.

Mary: It wasn't for her. It was for us really. Like, she had no clue.

Paul: We begged the doctors. We said we just want to have her home one more time, just for us. And he was like, "I don't know." I'm like, "What! We cared for her for five years. Nothing's going to happen to her once she's there." And he said, "Well, you know, she's still my responsibility." I went, "Listen, just do this one thing for us." So, she came home, one last time.

Martha: One of the workers . . .

Mary: . . . came with her. Our favorite one came with her.

Paul: So she was home for a little while. And we took her out in the back yard and she did her laps. I mean, she would just walk and walk and walk.

Martha: Because we knew that she was getting —

Paul: That was it, yeah.

Mary: . . . to a point where we would never have her home again.

Martha: It was — yeah, it was definitely for us.

Paul: Going to visit her was really hard, because she wouldn't sit down. She would roam the halls . . .

Martha: . . . all day . . .

Paul: . . . unless she was sleeping.

Mary: We'd have to follow her around with food to feed her.

Paul: She was on, what, 30 combinations of different medications? They would say, "We're going to try this new combination [of meds], what do you think?" And we'd say, "Okay," because we were trying to get her to a point where she could go to a nursing home. Then, a couple days would go by, and they'd say, "No, that didn't work." I'd get another call and [they'd say], "Now we're going to try shock therapy." And that worked for, I think, about a week. Calming her down, I mean. Then, she just went back to walking, pacing really, and yelling.

Christine: It was a locked ward?

Mary: Yes. That was the thing about our Mom, even when she was pacing, even when she couldn't talk or express herself, you could feel how loving and caring she was. She'd give you hugs and kisses. They all

got very attached to her, the nurses, the social workers, the doctors. They've said to us that she's their favorite patient.

Martha: Like her nurse was probably around the same age as us. And she had a mother; her mother was about the same age as our Mom. So she had a real hard time with what happened to my Mom.

Christine: You mean about medicating her with morphine?

Martha: Yeah, a real hard time.

Mary: She actually refused to.

Martha: There was a very emotional meeting. We said, "You have to understand — if she doesn't want to live like this, we don't want her to live like this. And to have her carry on the way that she is, it's not fair to her, or to us."

Paul: Towards the end, before she went into the hospice, we talked about morphine and all these other drugs. We had to meet with Dr. Brendel [the chair of the ethics committee at McLean Hospital] and we had to write a statement [see "A Letter from the Children"].

Martha: And we had to go in and have meetings about ethics.

Paul: We can give you all that stuff. I have it all on the computer. I can e-mail it to you.

Christine: Thank you; that would be great. What did you write in your statement?

Mary: It was about what we wanted for her.

Paul: I'd have to re-read it, but yeah, we talked about our mom, what type of person she was. We wanted them to understand why we were making the decision [about giving morphine] that we were making, because she wouldn't want to be living this way, and it was no type of life and no quality of life for her to have, to just be walking around aimlessly. I mean, she started to get really sick at the end, and I felt like she was suffering. She was just always riled up. Her chanting and her walking and her pacing, and she was never calm. Maybe she was trying to tell us, "I just want to be peaceful," because she wasn't.

Martha: Yeah, she was never at peace.

Christine: What did you want your mother's caregivers to do?

Paul: I would probably say to the medical profession and people in the nursing field: do everything you can to save someone; but in a case like this, the thing to do is to just let them go. Sometimes, you people shouldn't . . . everything *shouldn't* be done. *Don't* pull out all the stops, because it isn't necessarily the best thing for everyone. At the end we said, "Listen to what we're saying. We're her voice, okay. We're telling you what's best for her."

Christine: What happened when you had the ethics meetings?

Paul: I mean, we sat down with, like, the state. We sat down with everyone.

Mary: Everybody under the sun — from the Alzheimer's Association, Dr. Brendel, Dr. Brendel's colleagues. I mean. . . .

Martha: It was funny because everybody that we met had the same reaction. The first thing that they would say is, "Oh my God, you're so young." Like every time. So many people said to us, "We're so amazed with what you've done for your mother." For us, we were young, our mother needed us, we didn't know anything different. We needed to take care of her. We just put our lives on hold.

Paul: It makes you mature really fast. You give up a lot of stuff. I would do it all over again in a heartbeat, you know, to make sure that she got everything right. But it really makes

you put everything in perspective. You know, money, houses, cars, all that stuff. I have a totally different outlook than if I — if this didn't happen to me.

Christine: So you had meetings with the ethics committee?

Mary: Yeah, and that's when we had to write that letter to explain ourselves to everyone. I can understand their side of it. But . . .

Christine: What was their side?

Paul: I think a lot of them worried, "What if this is a Terri Schiavo case?" You know, what if the news [people] got wind of something like this? When we met with them, they all felt for us. A lot of them got to know us really well, because we pretty much poured our life out to them. We told them everything about us; what we've done and what we haven't done. What's worked; what hasn't worked for our mother. A couple of people said, "What you guys are doing is the right thing." Not for every case do I think it's the right thing. But for someone who was as loving and caring as our mother, and then to see her in this state — we talked a lot about dignity.

Mary: When it came to the end, before the idea of hospice came up, [the staff at] McLean started to say "Okay, well, we'll consider end-of-life care." But they're a mental health facility; they're not a medical facility. So they weren't equipped to deal with her. So that's a lot of the reason behind all those ethical meetings.

Christine: Were they upset about giving your mother a lot of morphine?

Paul: Some of them were.

Mary: Yeah, some of them definitely were. But she wouldn't eat, and she was always upset and restless.

Martha: She was never a tiny woman, but when she first went into the hospital she was like a size 14. And when she died, we actually had to go buy her an outfit because she had lost so much weight, and we bought her a size six.

Mary: Me and my sister said, "She'd be so pissed that she couldn't enjoy this!"

Christine: Did you feel upset with the nurses that wouldn't agree to give her morphine?

Martha: We were aggravated.

Paul: Yeah. I was angry, to be honest with you. You know, I was like, "Who the hell are you to tell me what my mother wanted . . . " you know, "and what we want for her, and what she wants for herself?" You know, it's almost like we have no right.

Christine: What did they say?

Martha: Her main nurse, the one that was the same age as us — later, she told us that her mother had cancer or something like that. So it was very personal for her, that she didn't want to be involved in using the morphine to let our mother die.

Christine: Did you all talk to each other about euthanasia?

Paul: Yeah. I mean, is that what we did? I don't know. I don't think it is, but . . .

Mary: It was more of an afterthought. I think at the time we just did what we thought was right. And then, you know, people started saying stuff to us like, "How could you have done that?" I mean, it was just a few people, but it was after the fact. And we were like, "Well, what did we do?"

Christine: People in your family? Or people who were taking care of her?

Martha: Probably a little bit of both.

Paul: The other thing is, it was just us. My mother has brothers who are alive and well, and her mother. And they just completely washed their hands of the situation. Right before she

went into hospice, we did the Memory Walk. And we were trying to get our family involved in that. And they were kind of like, "Well, what's going on?" I remember [Martha] talked to our aunt and uncle about moving her to a hospice. And they said, "Hospice, what are you talking about?" And then my aunt had to leave the room because they couldn't be actively involved. So it was just us.

Martha: We invited them to the meetings that we had at McLean and everything; but there were always these excuses, like, you know, "I can't leave work today."

Christine: Did they just not realize that she was suffering or dying?

Mary: I think they chose not to.

Christine: Did they think you did something you shouldn't have done?

Paul: I think one of our uncles had that impression until everything came out [at the funeral], and we gave a eulogy at the Mass for her. He came up to me after and said it was beautiful. I don't think he really understood the extent of what was going on with her.

Christine: What happened when she went to hospice? I know there was some discussion before she went, asking them in advance if they were willing to do terminal sedation.

Paul: Well, [our mother] was still very active. I mean, she was strapped into a chair, and she was very loud and . . .

Christine: At McLean?

Paul: Yeah, at McLean. And even the first day she went into hospice, I remember the nurse practitioner came in and he said he wouldn't have taken her if he had realized how bad she was. And I got right on the phone and called [the social worker at McLean], because we were like, "Oh my God, what's going to happen to her?"

Mary: Yeah, "Are they going to back out of this?"

Christine: What happened?

Mary: When he came to see her [at McLean], she had been medicated and she was quiet. And then she walked into the hospice screaming. And we thought, "oh no!" you know?

Paul: Then one night they called us [from the hospice] and we all rushed over. We didn't think she was going to make it. They said, "We're going to bring her to McLean. You guys can go home." And I'm like, "I'm not going home." We had the priest come, our family priest, and he gave her the Last Rites. And even as we were praying with her, we kept checking, "Is she still breathing?" Like, you know, because she would breathe, and then she wouldn't. And then she would breathe, and then she wouldn't. It was scary to watch. Then reality set in: "She's not well, you know. Look how she's breathing." And we had another nine days after that, right? She'd be breathing and then she'd stop for like 30 seconds, you know, and then she'd start breathing again. So I'd stay there [in her hospice room]. . . .

Martha: Yeah, he wouldn't. . . .

Mary: . . . he wouldn't leave.

Christine: Sons and mothers.

Mary: They have a little booklet [at the hospice] about what to expect when someone is dying. And they kept telling us to tell her that it's okay for her to go, that we will be okay without her, and that we love her. So we were talking to her. And we thought, "She's not going to die."

Martha: And then there were little things like, I swear to God, she said "[Mary]" a couple days before she

died. Her eyes were closed, but she was reaching out. And then she just sat up, and I swear to God she said "[Mary[," and then laid back down.

Christine: What's so hard is not knowing when it's really the last breath. I don't know what happened to your mother, but a lot of times when a person is dying they will take a breath, and then it'll be minutes, minutes, and you've just convinced yourself that they've died, and then they go "Aaah," and start breathing again.

Paul: Yes, exactly, that's the way it was.

Mary: She'd start breathing again.

Martha: They told us that she would die with who she wanted there, and [Mary] and I weren't there. I don't know if I would've been able to handle it.

Mary: I don't think I would've . . .

Martha: He [Paul] was there. And her favorite aunt and husband — they had stopped by after church.

Christine: What happened?

Martha: I just know he [Paul] called us and said, "You better come now." And when we got there, he was standing at the doorway. And I knew. I knew when I was going there. Because when I was getting dressed in my room, I started coughing real hard. I just had this feeling. I looked at the clock, and when I got there, it was the same time. I asked [Paul] what time she died, and it was the same time that I started coughing really hard in my room. It was . . . she was gone.

Mary: She died on a Sunday. I mean, my mother was very religious. We're Catholic. And they say people that die on a Sunday go straight to heaven. So we're like, "Oh, it's a good thing she got in on a Sunday." I don't know if it's true or not, but I believe she went straight to heaven.

Christine: So after you had the funeral, did people in your family stop saying things about the medication at the end of her life?

Paul: Actually, it more intensified.

Mary: Yeah, it got worse: "How can you do that, put her in the hospital like that and put her in a nursing home and let her die?"

Paul: People are very critical when they're not in the position to really understand. It was upsetting to hear people saying things. Then you question what you've done; like, "Did we do the right thing? I mean, did we care for her the right way?" Then we would get angry, like, "How dare they make us question our decisions, things that we knew that our mother wanted?" But you second-guess yourself, you know, when all these people are saying things. But my mother had stated what she wanted, you know. And if we didn't follow her wishes, then we would've been doing her an injustice.

Christine: Do you think it was the medication that killed her?

Paul: I don't. . . .

Mary: She [her disease] was so far along, and we didn't even know it. To us, it was really fast for us. Five years sounds like a long time, but it's not really. We had five years; bang, it's over, she was gone.

Martha: They had told us she would forget to swallow and forget to breathe. And that's what was happening at McLean Hospital. So. . . .

Paul: I don't think that the medication killed her. I think that if she had to be intubated and then put on a machine, there might've been a possibility that she would've lived a month, maybe longer. But she was so far along.

Martha: We had an autopsy and donated her brain. They said it was severely atrophied, and there was something

about the brainstem, I think, as well.

Christine: Do you have pictures of her?

Martha: That's all her [pointing to a glass-covered collage of photos on the coffee table]. This is her, the Mom we remember. . . . That's her, you know, just being goofy. And that's her . . . she loved animals. That was our family dog. That's her wedding picture. She was very beautiful. That's when she was sick. This is the day that she realized that she wouldn't go back to work, and they had a little party for her. That's her in the middle. They gave her a plaque, you know: "Great friend and Great worker." It was a really emotional day. And that's her nursing school graduation. This is the time we brought her home from the hospital, just for the day. She's young, here. . . .

Attention to Caregivers and Hope: Overlooked Aspects of Ethics Consultation

Ruth B. Purtilo

On occasion when working in my role as an ethics consultant I walk into a situation and think, "Everyone here is *in extremis,* not just the patient but the family and professional caregivers too!" Fortunately it is not always the case, but when it is you can see it in their eyes. And when I recall my clinical years, working in a rehabilitation setting with people who had dementias and traumatic brain injuries, I can bring back the faces of patients and families who slipped away from the professional team's grasp — we who wanted so much to be of some significance in their individual and collective quality of life. I can conjure up, too, a creeping dread, a prickle that started at the base of my spine, that we clinicians were impotent at times to be of much use, even to those who showed great kindness to us for our sincere and arduous efforts.

The narrators of "Margaret's" and her caregivers' stories convincingly convey the extremity into which everyone was cast at one time or another by Margaret's condition, and how those times compromised the ability of professional and family caregivers alike to sustain some modicum of certainty that what they were doing was right for Margaret — or themselves. No reader would conclude that during the months leading up to her transfer to hospice, where she spent the last 10 days of her life, that this was "business as usual," not even for stressed family members or clinically experienced professionals. For example, we are reminded that the institutional context itself — a psychiatric hospital — was an added disorienting factor for clarifying the issues that are usually addressed in end-of-life care.

At the same time, the narrators describe how a family and team of health professionals can show astonishing creativity in their approaches. Woven into the telling of this story are the numerous ways in which this group continued to keep strong links in their human chain of support for Margaret over the course of many months, including instances when professional and family caregivers felt genuine appreciation for each other while struggling with strong differences in judgment.

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Many of the ethical issues raised in the long course of Margaret's care are chronicled in the previous pages. This gives me an opportunity to highlight two aspects of Margaret's story that warrant our attention. Because the role of the various (and, in many cases, numerous) caregivers is essential to a fully informed positive outcome, I first want to shine attention on some caregivers' challenges that I believe should be taken into account in deliberations such as the ones that faced the ethics consultant in the story under review. Second, I want to raise some important ethical quandaries that surface when the patient has a chronic and progressively debilitating cognitive condition such as Alzheimer's disease, when there is not only increasing impairment over an indeterminate amount of time, but also an outcome of inevitable death.

Any observer of Margaret's course surely has to appreciate the caregivers' efforts and successes, as well as sympathize with their lingering concerns and queries. As a clinical ethicist, it would be within the scope of my usual and customary practice to affirm them by commending each for bringing his or her skills and involvement to bear on Margaret's onerous and exhausting situation, and leave it at that. Indeed, in many clinical ethics analyses, that is precisely where attention to family caregivers and professional caregivers remains, either as the source of important background information (for example, social or clinical history) as a report on current medical status, or as a crucial instrument to the development of the real story line — that is, what is to become of the patient. In this mode of analyzing a clinical story, Margaret is the main character, and the supporting moral actors exit and enter at various junctures in *her* life. But within clinical ethics, an ever-maturing knowledge and understanding are emerging that this approach, taken alone, often fails to give adequate shape to the core issues, and therefore creates a risk that the consultation may veer off course when a critical recommendation is to be made. The narrators of Margaret's story articulately convey how the contours of the situation finally were fleshed out in the bodies, words, and experiences of Margaret, *but also* those of her children, of the physicians, and other professional team members. A recent book review in *Gerontologist* notes, "six books have been published in such a relatively short time span and all address some level of the psychosocial aspects of Alzheimer's more than the biomedical [aspects, which] symbolizes a reawakening of what makes us all human: the need to relate to others in a meaningful way."[1] In acknowledging the weight under which everyone caring for Margaret was struggling, the narrators of her story were able to raise pertinent questions and begin discernment about what to do, that mattered, in this moment, occasioned by a woman who fell into dire need of professional care.

There are two groups of caregivers, each with their own challenges and essential roles: family and professional caregivers. In some writings, they are referred to as *informal* and *formal caregivers,* but I think these categories can serve to divide their functions into "silos," which may not accurately reflect the web of caregiving that takes place.

Family caregivers easily can be taken for granted as simply doing their job in advocating for the patient, no matter the personal cost. No one would argue with Stephen G. Post's observation about the family's role in the care of persons with Alzheimer's disease, that "once care is in place, the issues that emerge in the natural course of the disease can be addressed in an informed manner. Informal family caregivers are vital in the culture and practice of care."[2] The benefits for Margaret were manifested through the conduct of her three children. Their choices fit the profile of my own previous observation, "When faced with a loved one who shows the debilitating effects of Alzheimer disease, most family caregivers initially rise to the occasion with remarkable courage, good spiritedness and, if all else fails, resignation. They often enjoy the admiration ('regard') of others on the basis of having assumed this new identify."[3] However, I believe the "crunch" comes when the need for care perseveres over time, as it did in this situation. Dementia caregivers often find that their personal (including financial) stresses increase as support begins to fall away, leading to isolation. As one wife noted of her husband's

worsening condition from Alzheimer's disease, "We no longer meet with our friends. Entertaining became a disaster. Our social life is gone."[4]

In spite of psychological, physical, financial, and social stresses, the peculiar psychology and morality of familial duty persists in the face of unexpected or prolonged caregiving, with sometimes untoward consequences for the caregiver. As I noted elsewhere:

> An all-too-often devastating long-term effect is that attention to other vitally important aspects of the caregiver's identity become . . . *dis*regarded, with social *dis*respect leading to marginalization quickly ensuing. Neglect over time replaces the initial attention afforded "heroic" caregivers to the point that their own basic needs are ignored and their contributions unappreciated. Study after study reveals that the everyday lived reality of most family caregivers is governed by society's belief that the family member must now accept a role characterized by his or her unbounded obligation toward the affected loved one.[5]

Abel has argued that this societal attitude long has been deeply engraved in social roles and expectations worldwide, especially for women caregivers, and persists to the current day.[6] Given these patterns of societal expectation, that a family caregiver is expected to shoulder the burden of the other's well-being at all (personal) costs, the clinical ethicist should take uncommon measures to assure that family caregivers do not become unnecessarily marginalized members in the consultant's and clinicians' attention, which can make a patient the sole focus of concern, when the family may be the only window to the patient's wishes and well-being. Disregard for family members need not be expressed directly for them to feel it, but may be expressed through inadvertent slights regarding their comfort, sensitivity to some topics, or an overall tone that suggests, this is "about the patient," not them. For example, I recall one African-American man, the spokesperson for his family in the decision they had to make for their mother, saying quietly as he looked around the room at the consult team, "I'd feel better if I saw at least one Black face among you."

What, you ask, should a clinical ethics consultant do to assure that the family caregivers' situation is acknowledged? Each caregiver needs to be commended by the ethics consultant for doing his or her best. Each needs to be acknowledged as having stayed the course of care under extraordinarily cumbersome and trying conditions. Each needs to be assisted in gaining access to accurate information and assistance such as is available through professional or community-based organizations. Each needs to be seen as someone who may benefit from counseling by a religious advisor, social worker, or other resource available in the healthcare setting. The clinical ethicist should not be exempt from joining others in trying to help the family identify such help. At the same time, ethics consultants sometimes can help by verbally acknowledging that a family member may be speaking or acting from exhaustion, by offering encouragement to family members to "hang in there" when they can, and by giving a family member permission to "drop out" for a time to regroup. Weaving these human dimensions into the process of consultation, to avoid family members feeling (or being) marginalized, is as crucial to a successful result as the usual focus on clinical details.

Professional caregivers may face a similar marginalized fate when a crisis of the type facing "Margaret" and her family arises. Generally speaking, the other-regarding morality of due care in professional oaths and codes keeps attention focused on the patient. Selflessness long has been a cardinal virtue of the caring professions. All too often, however, the emotional and physical wear and tear on professional caregivers is ill attended to, at great personal and social cost to them, especially (although not exclusively) in situations such as Margaret's. As O'Brien notes, "Institutional caregivers experience frequent and early burnout dealing with patients with whom they cannot communicate well, who are unappreciative, who resist the caregivers' efforts to help. . . ."[7]

The likelihood that those caring for Margaret for six months were worn down is very high

indeed; some reasons are articulated in the narrative. *Six months* of attempts to quell her symptoms, which included lunging, screaming, and falling to the floor as dead weight, while the incessant march of her disease continued to express itself in new sources of clinical concern, right through winter and spring, on days with staff shortages and other patients who needed attention for equally compelling reasons. Professional caregivers also were paying attention to the patient's family. On one side of the coin, their focus on the patient and family is a textbook description of expectations consistent with their professional role. On the other, the underbelly of neglect for the professional caregivers' and aides' needs to cope well over time is exposed, with the negative effect this may have on the whole clinical and moral effort of caregiving.[8] Difficult-to-manage patients who have troubling symptoms or behaviors may engender feelings of avoidance, dread, or even revenge, hardly the attitude to sustain high-quality caregiving.[9]

A clinical ethics consultant may fear that expressions of sympathy or other attention to the plight of the professional caregiver will appear paternalistic or misplaced. They, after all, are the ones who call in a consultant's assistance, serve as problem-solving partners during the consultation, and often are the ones who take recommendations back to the patient and family to decide on a course of action. But this should not preclude attempts on the part of the ethics consultant to acknowledge the human stresses that the professional caregivers are facing. It may be as simple as a statement to the effect that this is a very challenging situation indeed, even on the end of the curve of situations that require ethics consultation, and that taking care of each other should be high on the priority list. Some clinical ethicists have worked with psychiatrists or others in more formal sessions designed to allow caregivers to express their frustrations. Follow-up calls or visits after the consultation to see how things are going also may convey the consultant's support.

In short, what we see in this situation is that the progressive and extreme symptoms of Margaret's Alzheimer's disease occasioned an extraordinarily intense response on the part of key caregivers — responses motivated by love, habit, social pressure, professional duty, moral disposition, and maybe others — but all geared to riveting attention on her for days, weeks, and months. They will feel supported by the ethics consultant's well-placed compliment regarding the contribution they have already made to the patient's well-being and acknowledgment of the specific emotional, physical, or other burdens they may carry in their attempt to care for her. These may be what the caregivers need to gather their energies for Margaret's future care, and give them the courage to take the next step.

These suggestions are set against the backdrop of urgency and a focus on outcomes at the price of process that clinical ethics consultations can easily fall into today. Best practices in ethics consultation, as in other aspects of healthcare deliberation designed to uphold quality of care, require that the press of time be pushed back in the interest of being thorough with issues that matter. Failing to pay attention to caregivers in such situations may compromise the quality of the consult and of the care provided.

In the remainder of this commentary, I invite you to consider some threats to hope in situations of high uncertainty, and to consider how an ethics consultant may help all persons in such situations to maintain hope. My assumption is that hope is an important but sometimes overlooked resource in ethical decision making.

T.S. Eliot wrote that, for many of us, the period between two certainties is one of the most anxiety-producing of human conditions, the place where "falls the shadow."[10] When it is certain that debilitating symptoms will increase and death will come, but there is great *un*certainty about when the release (of death) will ensue, the shadow falls on everyone involved. It falls longer when caregivers believe it is their duty to create a zone of certainty to guide judgment towards beneficial, morally justifiable action. If we view Margaret as representative of a rapidly growing population of patients whose disease trajectory takes a course of prolonged, progressive debility between diagnosis and death, the situation urgently calls for an ethicist's attention.

In Margaret's story, one critical shadow of uncertainty is the caregivers' lack of knowledge about what Margaret would want. Margaret's advanced directive was not found until after her death, and she had reached the point that she could no longer speak for herself. Another shadow comes from her behavior. Is she suffering? Is there pain? Is she dying? The caregivers aren't sure. They know, yes, she will die from her disease, but the moment that palliative interventions that are appropriate for end-of-life care are suggested, the family and some of the professional caregivers move in one direction — and some in the other.

Certainty helps one to know where to focus realistic hope, using it as a resource for enduring shadow experiences of high anxiety while gathering information and energies to take an informed next step. A basic ingredient in the training of health professionals — that professionals are harbingers of hope — must always be maintained. Health professionals themselves find hope (and take comfort) in their ability to turn their focus solely to comfort and end-of-life measures when recovery is no longer a practical goal, and in knowing that they are proceeding in a manner that is considered to be ethically permissible.

Margaret, her family, and her professional caregivers seem locked in hope-limbo, the latter not knowing or agreeing on where to direct their hope — that emotional light on the right course to pursue. Her situation did not include certainties that would allow morally competent and morally sensitive professionals to proceed with confidence that they were meeting their duty of caregiving, which includes being a source of hope to the family.

The dilemma of "what to hope for" was not simply a matter of a failed attempt at cure: that moment when patient and all caregivers have to check their compasses and gear up for the next climb toward palliation. It was a paucity of footholds as they found themselves slipping down the steep banks of uncertainty. As one social worker put it during a recent seminar on chronic care, while talking about her work with a woman whose husband was showing signs of serious AIDS neuropathy, "She said they've always been a praying family when trouble hits. But she's having trouble praying! She doesn't know what to pray for because she doesn't know what to *hope* for. And I had to agree it could be difficult. I'm told he could live for several years, or die anytime. The whole encounter left me feeling defeated, because as I tried to think about it, I couldn't say what I thought there was to hope for in that moment either! There's always the religious hope that God will be with you for whatever, but somehow I didn't feel like that was what was called for in that very moment!"

A "hope dilemma" can present a serious challenge to good patient care. Clinical ethicists often experience the tendency of caregivers caught in such a situation to try to reduce the ambiguity and anxiety of the situation by imposing certainty where little exists. One common response among family members is to "go for broke," insisting on every intervention. Didion reflects this stance in her essay, "The Case of Theresa Schiavo," in the *New York Review of Books* when she observes of the parents' position, "There was the unassuagable grief of the parents, the fierce parental need to construe any abandonment of hope [for her continued life-sustaining interventions] as a betrayal of their firstborn child."[11] Another is for the family members or health professionals to move towards palliative end-of-life care, often with the anxiety that they have given up prematurely or inappropriately, moving out of the scope of morally permissible action. Recall that this was a concern for some of the professional caregivers in Margaret's situation, which left them with questions while the family members expressed relief.

Increasingly today, the hope dilemma is being articulated in ethics consultations. Some comments I've heard in recent weeks include, "One of the problems is that the family is still clinging to the hope that she will not linger, but go quickly," or, "They can't let go of hope [for her recovery]." The rub is that the ethics consultant, too, does not know what to *do* in many situations when hope is elusive. Occasionally, bringing caregivers and family together for an ethics consultation will reduce uncertainty because additional information is obtained, or

values are expressed, or new goals offered, as the health professionals and family have a more concentrated exchange. Often participation in the consultation process is a source of comfort to all, even though the clinical diagnosis and prognosis remain unknown or uncertain. I believe that while increased clinical certainty and a deeper understanding of the issues always help to sustain and focus hope, the personal interaction that takes place in ethics consultation may support hope when one result is reassurance that family caregivers and their loved one will not be abandoned by the healthcare team during their time of difficult decision making, while they are under a shadow of uncertainty.

Everyone knows that consultations take time in an environment where time is literally money. I learned a lesson about the power of taking time while visiting an Alzheimer's Unit of a local hospital. A social worker was hurrying down the corridor ahead of me, but stopped upon seeing a very worried-looking family huddled near the lounge. "Is something the matter?" I heard her say. A young woman replied, "We don't know what's happening and everyone is too busy to tell us." The social worker pulled up very tall and responded reassuringly, "*I have time.* I may not be able to answer your questions, but *I have time* to hear them." There was visible relief on every face. Taking time, making time in an ethics consultation for the concerns of professional caregivers and families to be heard in one place, for as long as it takes, may also serve as a means of discovering where they can place hope.

Margaret's story reminds me that the traditional sources of hope that come from a predictable progression of symptoms and a clear prognosis often are not available to a family or to professional caregivers. Should the clinical ethicist offer reassurances that support hope? I believe the answer is yes. Acknowledging that it's hard to know what to hope for in some situations may help a health professional or family caregiver to place a portion of his or her anxiety into perspective. Reassurance that an ethicist or the ethics team will abide with the patient, family, and health professionals may help maintain their hope that they will not be abandoned.

The depletion of hope among caregivers is relevant information in an ethics consultation, and vigilant sensitivity to their hope and hopelessness can become an essential part of ethics consultation.

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Suffering in Advanced Dementia: Diagnostic and Treatment Challenges and Questions about Palliative Sedation

Jeffrey T. Berger

"Margaret" appeared to be afflicted with Pick's disease, a form of dementia that is often associated with personality changes; the age of onset for Pick's is 10 years earlier than Alzheimer's dementia. Margaret's family had her admitted to a psychiatric facility for treatment of violent agitation. During this six-month stay, she was noted to have intermittent vaginal bleeding. Although the palliative care consultant was aware of the bleeding and wondered if Margaret had a gynecologic source of pain, her physicians did not pursue this possibility. They may not have fully recognized the potential relationship between bleeding, pain, and agitation. Pain is a well-recognized cause of agitation, combativeness, and increased vocalization in demented patients.[1]

Vaginal bleeding and pain syndromes may be caused by a number of conditions including endometrial cancer, cervical cancer, or even uterine fibroids. An ultrasound of the abdomen is a simple and non-invasive test that may have helped Margaret's physicians identify the cause of the bleeding, as well as the source of her pain. Information from an ultrasound may have assisted in the development of a more effective palliative treatment plan, improved cooperation from the nurses in providing narcotic medication, and may have helped the family in at least two other ways. First, assuming that the bleeding was from a uterine malignancy, Margaret's daughters would have found this information relevant to their own personal health. Second, it could have helped the family make better sense of her behavior.

Why did Margaret's physicians leave her vaginal bleeding unaddressed? We can only speculate. Medical decision making is highly complex, and it is well recognized to be compromised sometimes by one or more cognitive shortcuts. For example, the *availability heuristic* describes a tendency to limit decisions to choices that most readily come to mind, and the *anchoring heuristic* describes a tendency to limit decisions to initial or established impres-

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sions. Research on judgment and decision making identifies numerous other challenges in decision making, such as biased thinking and framing effects.[2] These obstacles in clinical decision making give rise to the admonition attending physicians direct towards medical students: "You can't make the diagnosis if it isn't in your differential."

Hypothetically, if Margaret's vaginal bleeding led to a provisional diagnosis of uterine cancer, the palliative care physician, in anticipating difficulties in controlling Margaret's pain, could begin to discuss palliative treatment options. When traditional use of systemic opioids fails to control pain or other symptoms, an accepted but still somewhat contentious option is terminal sedation (TS). TS would have likely caused her to die sooner, since it necessarily causes the cessation of all oral intake, and the dehydration that follows usually causes death within a few days. Obviously, TS palliates both physical and existential suffering.

While it would be imprudent to comment on this case specifically, an alternative palliative treatment option for some patients with severe visceral pelvic pain is a hypogastric nerve plexus block that can provide significant relief in 70 to 75 percent of patients and allows for a 50 percent reduction in the use of systemic opioids.[3] Although the procedure, which involves inserting a needle through the skin to reach the nerve plexus, carries with it some risks and the procedure itself may be uncomfortable, it is generally recognized as safe and tolerable. For demented and agitated patients, however, sedatives may need to be administered to safely complete the procedure.

Even though Margaret's clinical course did not require use of TS or invasive palliative procedures, a dilemma that clinicians, patients, and families could conceivably face is the choice between these two options: certain and complete symptom palliation at the cost of earlier death or less complete pain relief at the cost of an imperfect, invasive procedure. Professional guidelines typically require that physicians make exhaustive efforts to palliate symptoms without compromising consciousness before resorting to TS.[4] Yet a patient, relative, or even a physician might ask: Should TS always be an option of last resort? Consider a patient with widespread colon cancer suffering from refractory nausea, vomiting, and abdominal pain due to a related bowel obstruction. A diverting loop colostomy is a relatively straightforward and effective palliative surgical procedure. Should TS always be the last intervention, or should other considerations, such as the patient's expected survival, the burdens of the invasive treatment, and expected extent of palliation, existential suffering, and patient's preferences, permit TS to be chosen over a nonterminal intervention?

What are physicians' professional and ethical obligations when a nonterminal invasive palliative treatment will preserve a quality of life that is not valued by the patient? Although TS has substantial support in the treatment of physical suffering, whether TS is appropriate for existential suffering alone remains quite controversial, particularly because, in the minds of many, TS abuts the boundaries of active euthanasia.[5] Does choosing terminal sedation over nonterminal invasive palliative treatments also blur the boundary between treatment and active euthanasia?

The case of Margaret illustrates some of the challenges often present in geriatric medicine and dementia care, palliative medicine, and end-of-life care. One challenge is to diagnose and treat patients who often are limited in their ability to participate in their care. Another challenge is to resist making assumptions about patients' or families' goals of care, because, despite many shared features among these kinds of cases, each one is unique. Lastly, a great challenge is for health professionals to work with patients and families in developing a consensus around care goals and for these professionals to work with one another to implement plans of care that are often ethically charged.

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Perspectives

What Is False Hope?

Daniel K. Sokol

Throughout the long history of the doctor-patient relationship, doctors have always had to break bad news to patients. It is only recently, however, that much attention has been devoted to this delicate art. Medical schools run classes on communication skills, and authors have written many books on the theory and practice of breaking bad news.[1] The common guidance is that doctors should be honest without being brutal, whilst all the while maintaining some hope in the patient, however grim the prognosis.[2] A distinction is often made between instilling hope, which is desirable, and instilling "false hope," which is not. But how is hope distinct from false hope?

To understand false hope, we must clarify the related notions of hope and expectation. Hope is typically a combination of two elements: (1) a desire that something will happen and (2) a belief that this desire could be fulfilled. So, although I cannot hope to be the fastest Jamaican sprinter in the world because I am not Jamaican, I can hope to be the fastest sprinter in England. Expectation typically refers to the belief that something is likely to happen. For example, I may hope to win the lottery (that is, I desire that my numbers come up and believe that there is remote possibility that they will), but I may not expect to win (that is, I do not believe this will actually happen). This distinction is encapsulated in the oft-heard advice: "You should hope for the best but expect the worst."

False hope arises when there is a strong dissociation between hope and expectation, when a terminally ill patient hopes for a cure *and* strongly expects that he will be cured, or, less commonly perhaps, when a patient hopes for a realistic outcome and pessimistically expects that it will never happen. The object of a hope — be it a cure for motor neuron disease or a multimillion lottery jackpot — does not determine whether or not the hope is false. What makes the hope false is the accompanying expectation and its relationship with what, objectively, is likely to occur.

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In a scene from the comedy *Dumb & Dumber,* the protagonist Lloyd, played by Jim Carrey, asks his dream girl to estimate the chances of a romance between them.[3] With a grimace, she apologetically mutters "one in a million." His face lights up: "So you're telling me there's a chance!" Lloyd's hope is false not because he wants to date the girl, but because his expectation, conveyed by his enthusiastic response, is higher than the situation warrants.

In medicine, talk of hope must thus be supplemented with talk of expectations, in particular managing patients' expectations. In instilling or maintaining hope, doctors should modulate a patient's expectations to avoid sliding into the realm of false hope, which may prevent the patient from exercising his or her autonomy (that is, from making decisions based on his or her own deeply held beliefs and values). This may be difficult when hope and expectation are at opposite extremes. Some patients may be totally unaware of the severity of their illness, waltzing into a consultation with high hopes that a pill or two will resolve the bothersome problem. Yet realigning a patient's hope with reasonable expectations is central to respecting a patient's autonomy and, although members of the public have no obligation to adjust even the wayward expectations of others, doctors are duty-bound to direct the health-related expectations of their patients.

"To hell with autonomy," one might retort, "and long live beneficence!" True hope might indeed be harmful and, at times, even more so than false hope. Anecdotes abound of patients who rapidly declined after their farfetched hopes and expectations were dashed. However, even on a harm/benefit analysis, true hope usually fares worse than false hope in the short-term only. Lloyd is happy in his fool's paradise for a while but when his *objet d'amour* mentions her husband, his heart sinks: "Husband? Wait a minute . . . what was all that one-in-a-million talk?"

Admittedly, there may be rare cases when it is preferable to raise expectations well beyond what cold reason dictates, and when false hope is kinder than true hope: in the minutes before a major, long-awaited operation, when the terrified patient asks if he or she will be all right, saying reassuringly that all will be fine; when a distraught mother asks if her child suffered in its final moments, saying that the child died peacefully; when a depressed patient contemplates suicide, lifting the patient's spirits with encouraging words.[4] If the two virtues cannot coexist, humanity should always precede sincerity.

In most circumstances, faced with the unenviable task of breaking bad news, one should maintain the all-important hope whilst guiding patients' expectations to a level roughly equal with one's best prediction of what will occur. It is a precarious juggling act, but a profoundly important one.

CONFLICTS OF INTEREST

The author reports no competing interests.

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