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# Patients May Benefit from Postponing Assessment of Mental Capacity

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In this issue of *The Journal of Clinical Ethics*, Daniel J. Brauner and Susan E. Merel present a highly nuanced approach to determining the mental capacity<sup>1</sup> of patients who have Alzheimer's disease (AD). In "How a Model Based on Linguistic Theory Can Improve the Assessment of Decision-Making Capacity for Persons with Dementia," they describe how careproviders can better assess these patients' decision-making capacities by using techniques such as listening for paraphrases and *anaphora* (words that refer to prior words), and conducting what they call "indirect repair and frame analysis." It is crucially important to find ways to better understand patients' capacity, particularly because patients may retain full emotional awareness even when they lose cognitive capacity. With better understanding, implementation of their preferences can be improved, allowing us to respond to them more as we do to patients who are clearly competent. In this way, we will be able to treat patients who have AD more justly.

But determining patients' capacity may have a downside: the patients may understand what careproviders are doing, and may infer, correctly, that the result may be that they can no longer make decisions for themselves. This may be something that a patient accepts or even wants; but many will not. Patients may experience the possible loss of being able to make decisions shattering. This may be so, in large part, because as the patients lose cognitive capacity, they find it more important to continue to have control. When patients fear control may be taken from them, it may abruptly end their capacity to feel trust, and they may no longer see their careprovider or other careproviders as allies, but as adversaries. This rupture in the relationships can extend to patients' loved ones, especially if the loved ones asked for the assessment, or just tacitly support it. This loss of feeling an alliance with loved ones may increase if loved ones later make decisions the patient opposes. As a result of an assessment, patients may lose not only their independence, but trust in others. Even when their choices are given great weight, these losses may completely change what they want.<sup>2</sup> Their new want may be for death, rather than for life-sustaining interventions. Several critically important clinical implications follow; I shall discuss these here.

## INTERACTION WITH PATIENTS

### Testing for the AD genotype

Persons may ask for genetic testing for AD before they receive a diagnosis of AD, and leading organizations have recommended that careproviders not refer them for genetic testing, if possible.<sup>3</sup> There are good reasons: the AD genotype, the APOE gene, is only a marker for susceptibility. Testing offers relatively little prognostic significance;

yet, if patients test "positive," they may become highly alarmed. Recent findings indicate that this recommendation perhaps should be challenged. In one study, adult children of parents who had AD were offered the opportunity to be tested; one-quarter wanted to be tested, and, of those who tested positive, 95 percent said they would do it again.<sup>4</sup> It has been a common belief until recently that research participants shouldn't be given access to results that have too little "scientific meaning," or access to results that do not meet the standards of statistical significance commonly used for providing medical care. It was thought that such results may be unduly harmful if given before then.<sup>5</sup> Innovative, eminent thinkers recently asserted that this approach may be wrong; they suggest that our present disclosure policies be reconsidered, in light of new data that suggest the levels of distress that research participants actually experience in these situations may be low.<sup>6</sup>

It is important to note that patients and research participants may find such results highly, personally meaningful. Some claim that persons who aren't scientifically trained can't adequately understand data when they lack scientific significance, but careproviders and researchers could explain what that lack of significance means, or, more importantly, what it does not. These considerations are exceptionally important to patients who want testing for the APOE gene for two reasons. First, when they may fear that they will acquire AD, it may be not this fear, but their uncertainty that is unbearable. For these patients, any degree to which they can relieve uncertainty may be a godsend. Helping patients to understand data should improve the patient/careprovider relationship, which may enhance the likelihood that patients will return for early diagnostic screening if and when they have memory loss, and for treatment, if they test positive. Also, if the relationship is positive, if and when the patients have AD, they may be more willing to listen to and follow their careproviders' advice.

### **Initial Screening for AD**

Currently, careproviders generally screen for AD when patients first complain of memory problems, and are at risk due to their age or to having family members who have AD.<sup>7</sup> Early testing is beneficial because medications now can slow the progress of AD. Careproviders can screen brief procedures, for example, a standard mental status exam that involves asking several questions, or asking patients to draw a clock showing a specific time.<sup>8</sup> Some patients may not want this testing.<sup>9</sup> Patients with AD are in some ways like the patients with incurable cancer that Paul R. Helft describes in his article in this issue of *JCE*, "An Intimate Collaboration: Prognostic Communication with Advanced Cancer Patients." The patients, he says, face an "extraordinary set of circumstances." They "possess a life-ending disease" and yet are still "functional and alive." He asks, "Is it ethically acceptable to support some patients' desires to avoid the cold, hard facts about their prognosis?"

Patients with AD also have a life-ending disease, but, in its earlier stages, at least, patients are functional and alive. They differ, in that, as they die, their capacity to function may markedly decrease. Careproviders usually conduct a brief screening for AD unless the patient takes the initiative to avoid it. In light of the "extraordinary circumstances" all patients may face, however, careproviders could ask all patients if they want screening. This may seem like asking patients if they want careproviders to take a medical history or do a physical exam, but making this offer furthers the interests of patients who don't want testing, but who will not take the initiative to avoid it. This approach furthers equity for less-assertive patients. These patients may come to feel greater trust for their careprovider as a result, and later may better accept what the careprovider recommends to them. The "price" of doing this is, obviously, when patients defer testing and treatment, their AD may more rapidly progress. Careproviders should always tell patients about this risk before they ask what they want to do.

### **Referring Patients for Further Testing**

The brief tests mentioned above have high rates of false positives and false negatives.<sup>10</sup> More elaborate testing can reduce both. An exam by a neurologist can rule out other, sometimes reversible, causes of memory problems or other symptoms that are common to AD. If the results of the brief tests are positive, patients can

be referred for further tests. If the initial tests are negative, careproviders generally reassure patients it is highly unlikely that they have AD, at least for the present. Some patients may remain highly fearful, and their careproviders may wish to depart from common practice and refer them for more testing. This is more respectful of patients' autonomy, and may enhance trust.

## **INTERACTING WITH PATIENTS AND THEIR LOVED ONES**

While careproviders strive to maximize the autonomy of patients with AD, they should also paternalistically urge patients to bring their loved ones to meet with careproviders as soon as they can. As Lyness says, "The diagnosis of dementia provides an opportunity to (indeed, mandates that we) engage in ongoing end-of-life discussions with the patient and family, and to begin doing so early in the course of the disease."<sup>11</sup> This may be most difficult when patients' relationships with their loved ones are at their worst — but that is when it is more important than ever.

When a patient and loved ones meet with the careprovider, they can discuss all the possible outcomes, best and worst, that may be encountered in the future, if this is what the patient and loved ones want to do. These discussions may help loved ones decide what to do, and to help them feel less guilty about the decisions they make for the patient after the patient loses decision-making capacity. To the degree that the patients' loved ones feel less worry, it will benefit the patients. It may be more important for patients and loved ones to discuss, when they still can, what each can do at different stages of the patients' disease to provide the patient maximum benefit. They should share three goals. (1) Loved ones should learn to defer to the patient initially, as long as what the patient wants doesn't "court disaster," and to continue this as long as they can. (2) As patients get worse and "court disaster," they should defer to their loved ones as long as they can. (3) At first, patients and loved ones should work together to alter maladaptive interactive patterns of behavior; later, loved ones should work independently to do so.

### **Persuading Patients to Bring in Loved Ones**

Careproviders should urge patients to bring in their loved ones from the outset. They can share with patients several rationales that will be discussed throughout this section. If a "logical approach" doesn't work, careproviders can try appealing to patients' emotions and — shamelessly — appeal directly to the patients' feelings for their loved ones. Careproviders can suggest that if they won't do this for themselves, they might be willing to do this for those they love, as it may, in one way or other, take care of them. The following is an example of an instance in which I succeeded in this way.

A patient in his late 40s had been briefly, involuntarily, psychiatrically hospitalized. He had been brought in by police the day after he told his wife he would take his life. If he was to be kept as an in-patient against his will for much longer, he needed to be formally evaluated. To keep him in the hospital, a court would have to declare that he was mentally ill, and a danger to himself. I was asked to assess this. The patient was initially suspicious and very withdrawn. I had learned from others, beforehand, that he had paranoid ideas. He adamantly denied that he was at all suicidal, and indicated to me that, above all else, he wanted to leave the hospital. Under these circumstances, I felt that it was most likely that a court would not be willing to continue to involuntarily commit him. Yet, I believed he really needed to stay there for a longer time to get the treatment he needed, so that he could get better quickly, or perhaps, get better at all. He said also in response to my specifically asking that, yes, he greatly loved his wife.

"She is scared beyond belief, I would guess," I told him. "She is scared that if you go home, you'll kill yourself. Do you agree?" I asked him. He did. I continued, "Even if you sign yourself out now, which I expect you soon could, and go home, what will it be like there? I expect she will be sitting there with you, but not feeling love, only terror. Is this what you want her to have to feel?" He agreed that he didn't. "The only way at all, I think, she could feel less afraid," I then said, "is if you leave this ward only when your doctors can tell you and her that they think this is safe. Even if, for yourself, you want to go now, the only way you can meet her needs is to stay here until that happens." Then the real guilt trip: "You would stay, if you are telling me the truth that you really care about her." He did.

### **Discussing the Future and Advance Directives**

Discussing the future and advance directives with patients and their loved ones during the earliest stages of AD can greatly benefit both. There are no limits to what can be discussed at this time; there is evidence such discussions do not cause patients to become depressed.<sup>12</sup> It may even be helpful to discuss what patients would want if they had to be kept in restraints, and what they would want if they could no longer eat by mouth. Careproviders generally are reluctant to pursue these kinds of discussions.<sup>13</sup> Regardless, such discussions respect patients' autonomy, and can help loved ones make decisions for patients later on, based on actual, expressed preferences, which frees loved ones from guessing and feeling undue, unavoidable guilt. There may also be some less obvious positive effects. This may, for example, help patients and loved ones to grieve. It may also help patients and loved ones experience greater bonding.<sup>14</sup>

The discussions may enable loved ones to make different decisions later on than they might have made otherwise. A particularly difficult issue is, for example, what to do should the patient lose the capacity to recognize loved ones, but seem to be happy in this state. This issue may be especially difficult to discuss if, under those circumstances, a patient wouldn't want the careproviders to maintain the patient's life. Patients may feel so strongly about this that, if they believe their wishes might not be honored, they might want to end their life before this comes to pass. This issue may be difficult, because even if a patient indicates his or her wishes unequivocally beforehand, if the patient appears to be happy later on, careproviders, an ethics committee, or a court may not be willing to withhold or withdraw life-preserving care. Some believe that patients in the initial stages of AD shouldn't be able to dictate advance directives that apply after they lose capacity, because, they assert, later on the patients are altogether different persons.<sup>15</sup>

Post argues, vehemently, against artificially sustaining patients' lives under these conditions. He believes that the patients may not be genuinely happy, and, even if they are to some extent, this state most likely will be very short-lived.<sup>16</sup> A compromise between these views may be the best: careproviders could keep patients alive, but only so long as they continue, as best can be guessed, to enjoy their lives, regardless of their prior preference; but once the benefit/burden ratio changes, such that patients have more pain, careproviders can allow them to die by withholding or withdrawing life-preserving treatments — unless, perhaps the patients indicated beforehand that they would want to stay alive in this condition. It is unlikely that loved ones would feel willing to implement this kind compromise unless they had discussed it previously with the patients. Discussing this situation may be exceptionally harrowing because, regardless of what patients and loved ones say in early discussions, it is possible that later, if the patients seem "happy" enough, the prior, joint decision could be reversed. Still, careproviders should discuss even this possibility with patients and their loved ones, if this is what they want.

Some patients still do "exhaustive" personal research on AD, even after they have suffered some initial losses.<sup>17</sup> There are many possible reasons; some may want to know all they can about AD while they still can, or even just because they still can. A less evident reason may be existential: knowing may be better than not knowing, when there is nothing else that a patient can do.

### **Helping Patients and Loved Ones to Help Each Other**

In time, patients' loved ones may provide care for them 24 hours a day. Consequently, the earlier they can learn how best to do this, the better the outcome is likely to be for both loved ones and patients. The following example shows what occurs, unfortunately, all too often.

Mr. C had mowed the lawn for years. After he was diagnosed with probable AD in the mild to moderate stage, his wife thought that it would be dangerous for him to continue. Thus, she locked the lawn mower in a shed. Later, Mr. C broke the lock, Mrs. C and their oldest son then removed the lawn mower. Mr. C thereupon found it missing and thought that it had been stolen. Mrs. C and this same son then explained what they had done. This same son and two other, younger sons afterwards came to join their parents, Mr. and Mrs. C, for their traditional Sunday dinner. When the oldest son arrived, "Mr. C uncharacteristically ignored him completely. When asked if he was angry with John, Mr. C replied that he was. When asked why, he replied, "I don't know." Mr. C had not, previously, behaved in such a way with his eldest son."<sup>18</sup>

Mr. C felt angry but didn't know why. Sabat, the author who related this anecdote, believes that Mr. C's anger resulted from what he calls Mr. C's "implicit memory" of what his son had done. Most importantly for the purpose of this discussion, this anecdote illustrates how patients and loved ones often don't know the best way to help each other, which can result in harm to patients. Sabat states, "Absent an understanding of implicit memory, it is increasingly likely that caregivers will engage in 'malignant positioning' [and] interpret that patient's behaviour as being dysfunctional when it likely may not be and [in doing this] exacerbate the problems that stem from the brain damage itself."<sup>19</sup>

During early discussions, patients and loved ones can learn to become allies, working together so that, in all instances, they can do the best that they can. During the first stages of AD, patients still have the capacity to learn how to do this. With their loved ones, they can anticipate what may occur, and, when it is helpful, alter what they might otherwise normally do. As the example involving the lawn mower illustrates, as patients' disease worsens, it is increasingly likely that their interests and those of their loved ones will conflict. One of the skills patients and loved ones can learn that may be most helpful when the earliest conflicts occur, is for loved ones to defer to patients' choices as long as they can. This possibility is illustrated by Maeckelberghe, when she states, referring to an 87-year-old man with AD, he "has certainly lost various abilities, [but] dependency should not be conceived as implying a loss of autonomy, provided that caregivers help him. . . . He is portrayed as a person who seems totally incompetent, wandering around. . . . It is possible to imagine a situation where the old man can actively live a life of wandering (after all, he has been physically active for all of his life)."<sup>20</sup>

Maeckelberghe's conclusion is quite relevant to the current discussion: "assessment of competence will not only be directed at this particular person whose competence is in doubt, it will focus on what means are being used in order to enhance someone's competence."<sup>21</sup> She presumes that it is often possible that loved ones' efforts can improve patients' capacity, and can change lives. Her reasoning is challenging: she states, "The female doctor who is asked about restraints for an 87-year-old man reacts differently whether this man is her patient or her father. As a daughter, the balance is different."<sup>22</sup>

As patients' capacity worsens, they may increasingly make poor decisions or act in ways that endanger themselves or others. When patients and loved ones discuss such possible situations while patients can still participate, patients may be more willing to defer decisions to loved ones when it becomes necessary — even when, at that later time, they disagree. At this time, patient may not be able to change their behavior or learn new skills, so this will fall to loved ones alone. Loved ones may, for example, unlearn dysfunctional beliefs. As Hepburn and colleagues note, for instance, loved ones may think, " 'Laying down the law' to my elder is something I must do," or, " 'I have the responsibility of confronting my elder with his/her mistakes.' "<sup>23</sup> Both of these beliefs are dysfunctional, as, in most case, they will serve only to "pour fuel" on patients' "fire." Hepburn and colleagues note that such beliefs may reflect the ways that loved ones believe they should respond, "based on social norms."<sup>24</sup> Rather, the authors suggest, loved ones can and should learn to base beliefs on "an appreciation of what the disease has done to the care receiver's capacity for performing in a socially acceptable manner."<sup>25</sup>

An example of a new behavior that loved ones might learn is to talk to patients while they are "feeding, dressing, bathing, or moving them." This may "personalize" the interactions for patients.<sup>26</sup> Loved ones may respond in negative ways that have become patterns, and so may be less easy to change. They may, for example, be passive-aggressive, expressing their anger with patients in ways such as "giving them the silent treatment."<sup>27</sup> Such habitual dysfunctional responses, over time, will greatly harm patients. Early discussion with loved ones can prevent this. As Lyness notes, "Depending on the family's needs, interventions may range from education and community referral to deeper interventions, such as restoring effective problem-solving, improving patterns of communication, or improving attachment and care-giving bonds."<sup>28</sup>

Loved ones who seek to help these patients as much as possible must become aware of how previous maladaptive behaviors can tragically worsen the care that they give patients.<sup>29</sup> As Kitwood noted, issues of "power, dependency, control, envy, jealousy, rage, fear, deception, disappointment, grief, fear [are and may]

need to be re-worked in [this] new context."<sup>30</sup> If loved ones don't pursue these goals, unresolved conflicts might lead loved ones to make decisions that they might not otherwise even consider. As Pochard and colleagues note, "The fastest way to obtain relief from ambivalence and uncertainty may be to make an end-of-life decision, which might be considered as an ethical risk."<sup>31</sup>

## **AFTER PATIENTS LOSE CAPACITY**

### **Postponing Assessment of Capacity**

As indicated above, it may be best, in some cases, for patients and loved ones to postpone a request for a careprovider's assessment of a patients' capacity, as patients may see such an assessment as proof that their loved ones and their careprovider think they are incapable of making their own decisions, and want to make decisions for them. If careproviders teach patients and loved ones early on how to discuss two tasks that they can accomplish together, it may be possible to postpone assessment. First, loved ones can learn to accept patients' "poor choices" so long as they aren't potentially calamitous. Second, if and when patients' choices become potentially calamitous, the patients may still be able to choose to defer such decisions to their loved ones. If patients can discuss this with their loved ones beforehand, and there is sufficient trust in them, patients may be able to do this, even though it means giving up what they want.

An example illustrating this second situation is when patients with AD can no longer safely drive. If patients can't see that they are no longer safe, this is a situation in which loved ones simply can't let them have their way. Continuing to drive would be calamitous. Yet it may be possible for loved ones to avoid having to ever overrule a patient. The patients and their loved ones may be able to discuss this situation long before it occurs; then, remembering these discussions, using whatever means they can to do this, patients may accept their loved ones' decision, even though they disagree with it.<sup>32</sup> The possibilities for this approach are without limits.

On the other hand, it may be possible for careproviders to assess patients' capacity without alienating the patients. That is, if careproviders discuss performing an assessment and its potential problems often, and in advance, with patients, the patients themselves may request a formal assessment for capacity, and may request it at the earliest, most optimal time. In the same way, if patients have early and repeated discussions with loved ones about making decisions for the patient in the future, if it becomes necessary, patients may request that their loved ones make decisions for them as their capacity to make decisions decreases. Rather than resenting their loved ones for disagreeing with them on a decision, patients will be able to see this process as something they planned, themselves, in advance.

### **Using a Sliding Scale to Determine Capacity**

When careproviders assess patients' capacity, they may use a fixed standard, or a so-called sliding scale. If they use a fixed standard, careproviders must apply set criteria, such as patients' being able to understand and state the pros and cons of their different alternatives. With a sliding scale, careproviders may be able to apply a more or less strict or demanding standard. They may use a less demanding standard, for example, when patients choose the outcome that will clearly provide them the most gain.

Since careproviders have greater flexibility when they use a sliding scale, this may be another way to postpone a determination that a patient lacks capacity, if and when this is desirable. Drane provides the basic rationale for doing this when he states, "A properly performed competency assessment should eliminate two types of error: preventing competent persons from deciding their own treatments; and failing to protect incompetent persons from the harmful effects of a bad decision."<sup>33</sup> A sliding scale may go further in eliminating the first kind of error. It may allow patients to retain legal competency to make decisions so that they can continue to decide for themselves regarding the treatments they want.

## AFTER THE PATIENT'S CAPACITY IS ASSESSED

*Careproviders can provide support by offering to help the patient's loved ones make difficult decisions.* For some time, careproviders have known that, if at all possible, they should support the loved ones who care for patients with AD, because, in addition to the benefits the provides loved ones, it benefits patients. Studies conducted over the last half decade indicate that loved ones may be traumatized when they make decision for incompetent patients.<sup>34</sup> Axoulay and colleagues note, "This contains an important message [that careproviders] are in a unique position for providing families with support."<sup>35</sup> Research indicates also that even though "caregivers frequently desire more support and reassurance from health care professionals, [they] may not often ask for help."<sup>36</sup> The implications for careproviders, once again, are clear.

Legally, loved ones may have the task of making decisions by themselves. Careproviders may offer their own views if loved ones ask, but there is also a good reason that they should be hesitant to volunteer them. First, loved ones may resent them taking this initiative. Second, careproviders' views may reflect their own, rather than the patients' or the loved ones' preferences. Third and most importantly, although careproviders have medical expertise, they may not have ethical expertise. Yet, notwithstanding these and other common and obvious objections, when careproviders offer their views, it may greatly help a patient's loved ones emotionally, if they can share both what they think and why. At minimum, careproviders should inform loved ones of the potential personal trauma they may undergo if they make decisions alone. Careproviders could also tell loved ones that they would be very willing to share their own views, if only to help loved ones reduce the trauma of making decisions, and not be so alone — if, but only if, loved ones want to ask.

Studies indicate that loved ones may be most vulnerable to harm as they make end-of-life decisions for incompetent patients.<sup>37</sup> Winzelberg and colleagues suggest that physicians could give loved ones "permission" to choose palliative care, so that "they may not feel the entire emotional weight of an end-of-life care decision."<sup>38</sup>

Finally, if patients' loved ones don't know that they could have careproviders' help, they may prematurely distance themselves from the patient emotionally, whether or not this is what they really want, because they anticipate the stress of having to make these difficult decisions. Careproviders can prevent such unnecessary distancing, which will harm the patients and the loved ones, by sharing how and why they are willing to help, early on. The stress of making decisions and its resolution may be additional topics that careproviders can pursue with patients and their loved ones from the very beginning.

*Careproviders can support loved ones by not using solely a substituted-judgment legal standard.* The previous discussion presupposes that loved ones will have some legal discretion in choosing what careproviders will do. This may or may not be the case. Loved ones may or may not have to decide, legally, solely on the basis of what they think the patients would want for themselves.<sup>39</sup> As this is the case, careproviders sometimes directly inform loved ones that they should not decide on the basis of what they want, for example, but only on the basis of what they believe the patient would want. But this is not what loved ones or careproviders usually do. According to one study, only two of 50 spouses of patients with dementia chose what to do solely on the basis of so-called pure substituted judgment.<sup>40</sup>

In another study, Hardart and Truog asked 327 physicians how they would decide what they would do for several kinds of patients who were incompetent. Some patients had dementia. A "sizable majority" of the physicians queried favored a strategy other than basing judgments solely on pure substituted judgment. Most said that they use a standard "not even offered as an option (let alone taught as a standard) in commonly read medical texts or the curricula of American medical schools."<sup>41</sup> Decision-making strategies that center on the family, not the patient, "may actually be more the rule than the exception."<sup>42</sup> Finally, Hardart and Truog asked physicians, "Should the medical system be refashioned to support, perhaps, even encourage, family-centered decision making?"<sup>43</sup> The pure substituted-judgment approach is, in principle, problematic for several reasons, but particularly so for patients who are incompetent due to AD, because they may be less able

to foresee what they will undergo and experience after they are incompetent — their brains may become impaired to a greater degree than most other patients. This difference is illustrated by the possibility that, rather than feeling worse over time, as AD progresses, the patients may instead become "happier," as described above.

As this is the case, careproviders may support loved ones when they prefer to use a strategy to make decisions other than the pure substituted-judgment standard. As one author says, "Physicians who discuss substituted judgment as the ideal decision-making principle may leave caregivers feeling conflicted. . . . Physicians should instead present substituted judgment as one of the factors considered by families when making decisions for loved ones."<sup>44</sup>

How can they do this legally? Careproviders could tell loved ones how the law works; that is, they could say, "We legally can only do what you believe this patient would have wanted. What this means is that if you think other factors should play a role, such as what you think is in the patient's best interest, you must state this as if this is what the patient also would want." Careproviders who do this are more clearly part of the decision-making process, so that loved ones may feel less alone, whether or not they ask careproviders what to do. If loved ones choose to use an approach other than the pure substituted-judgment standard, careproviders who do this will be "complicit" in helping loved ones "get around the system."

## CONCLUSION

When careproviders see patients with AD, most often a time will come when they must assess mental capacity. Before, during, and after this time, they may be able to offer a variety of assistance to patients and their loved ones. The core assumption underlying these approaches is that although patients have a disease that leads to progressive cognitive impairment, at all stages of AD patients are sensitive and responsive (to different degrees) to interpersonal cues. By remaining conscious of these interpersonal effects, and doing all they can to enhance the benefits that patients may gain, careproviders may be able to significantly enhance the quality, if not the quantity, of patients' lives.

## NOTES

1. *Capacity* refers to careproviders' clinical assessments; *competency* to the status legally determined by a court. If careproviders find a patient clinically to lack capacity, this usually will result in the court determining that the patient is incompetent.

2. R.B. Reilly, T.A. Teasdale, L.B. McCullough, "Projecting Patients' Preferences from Living Wills: An Invalid Strategy for Management of Dementia with Life-Threatening Illness," *Journal of the American Geriatric Society* 42 (1994): 997-1003, at 1011.

3. K. Wachter, "Genetic Screening for AD Appears Beneficial," *Clinical Psychiatry News* (February 2006): 26. See also, H.L. Paulson, "Diagnostic Testing in Neurogenetics: Principles, Limitations, and Ethical Considerations," *Neurology Clinics of North America* 20 (2002): 627-43; J.S. Goldman and C.E. Hou, "Early-Onset Alzheimer Disease: When is Genetic Testing Appropriate?" *Alzheimer Disease and Associated Disorders* 18 (2004): 65-7.

4. Wachter, see note 3 above.

5. L.S. Parker, "Rethinking Respect for Persons Enrolled in Research," *ASBH Exchange* 9, no. 2 (Spring 2006): 1, 6.

6. D.I. Shalowitz and F.G. Miller, "Disclosing Individual Results of Clinical Research," *Journal of the American Medical Association* 294 (2005): 737-40; D.I. Shalowitz and F.G. Miller, "In Reply: Implications of Disclosing Individual Results of Clinical research," *Journal of the American Medical Association* 295 (2006): 37-8.

7. Wachter, see note 3 above.

8. See, e.g., A.E. Pfeiffer, "A Short Portable Mental Status Questionnaire for the Assessment of Organic Brain Deficit in Elderly Patients," *Journal of the American Geriatrics Society* 23 (1975): 433-41; D.J. Connor et

al., "Performance of the Three Clock Scoring Systems Across Different Ranges of Dementia Severity," *Alzheimer Disease and Associated Disorders* 19 (2005): 119-27; U. Beinhoff et al., "Screening for Cognitive Impairment: a Triage for Outpatient Care," *Dementia and Geriatric Cognitive Disorders* 20 (2005): 278-85.

9. R. Adorno, "The Right Not to Know: An Autonomy Based Approach," *Journal of Medical Ethics* 30, no. 5 (October 2004): 435-9. See also M. Marzanski, "On Telling the Truth to Patients with Dementia," *Western Journal of Medicine* 173 (2000): 318-23; A.P. Smith and B.L. Beattie, "Disclosing a Diagnosis of Alzheimer's Disease: Patient and Family Experiences," *Canadian Journal of Neurological Science* 28 (supp. 1, 2001): S67-S71; R.C. Hamdy, "Alzheimer's Disease: To Tell or Not to Tell," *Southern Medical Journal* 97 (2004): 1.

10. P.R. Solomon and C.A. Murphy, "Should We Screen for Alzheimer's Disease?" *Geriatrics* 60 (2005): 26-31.

11. J.M. Lyness, "End-of-Life Care," *American Journal of Geriatric Psychiatry* 12, no. 5 (2004): 457-72, p. 468.

12. C.G. Lyketsos and J. Olin, "Depression in Alzheimer's Disease: Overview and Treatment," *Biological Psychiatry* 52 (2002): 243-52.

13. Reilly, Teasdale, and McCullough, see note 2 above; see, also, T.A. Cavalieri et al., "How Physicians Approach Advance Care Planning in Patients with Mild to Moderate Alzheimer's Disease," *Journal of the American Osteopathic Association* 102, no. 10 (October 2002): 541-4.

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