

## Deciding for the Patient

Mr. Jackson was a 64-year-old man with advanced dementia and newly diagnosed cancer of the head and neck. He was brought to the emergency room from his board and care facility with a history of not tolerating oral feeding. Mr. Jackson had a large mass at the base of his tongue, which was determined to be cancer. Further evaluation revealed spread of the tumor to his lymph nodes, rendering it incurable. He was not a candidate for chemotherapy, radiation, or surgical intervention.

Prior to the cancer diagnosis, Mr. Jackson's only major medical problem was advanced dementia. In the years following an initial stroke, he suffered a series of infarcts and had become mostly noncommunicative. His family, in-

cluding a daughter Joan and son Rick, believed he no longer recognized them. They did note that he seemed to enjoy their visits, smiling and responding positively to human touch and conversation. Since the obstructing mass prevented Mr. Jackson from eating or drinking safely, a decision regarding feeding tube placement was required.

Although Mr. Jackson had formally named both children as Durable Powers of Attorney for Healthcare, he had not completed a Living Will or specifically discussed treatment preferences with them. However, Joan and Rick said that following Mr. Jackson's first stroke he had wanted to kill himself if he were ever unable to feed or care for himself. Joan and Rick were unsure if Mr. Jackson had been depressed, but they noted

that he had been on some mood "pill" several years ago.

The medical team explained that Mr. Jackson's cancer was incurable, but with artificial feeding he could be expected to live four to six months. Also, if they denied artificial hydration (either via tube feeding or intravenously), Mr. Jackson would likely die within the next several weeks. The medical team made no specific treatment recommendation, although it acknowledged the difficulty of the decision. Based on the patient's poor prognosis and his desire to die if unable to care for himself, Joan and Rick elected to withhold both the feeding tube and intravenous fluids. Mr. Jackson returned to his board and care facility, where he died one week later, presumably of dehydration.

### commentary

by Shiri Etzioni and Ken Rosenfeld

Mr. Jackson's children's decision to forgo artificial hydration and feeding was based on statements he made several years ago, when he faced the prospect of disability. Both children felt their father would not have opted to prolong his life in his current dependent state. Did they take Mr. Jackson's current interests into consideration? Was the decision justified by his prior wish never to live a dependent life?

The evidence supporting a feeding tube for patients with advanced dementia is scant at best. Studies of dementia patients with feeding tubes have failed to demonstrate a benefit in survival du-

ration, nutritional status, or patient quality of life. However, Mr. Jackson's inability to eat was secondary to a mechanical obstruction rather than to his dementia. Since prior to developing cancer Mr. Jackson was able to eat with minimal assistance, a feeding tube would probably have prolonged his life by months. Thus, as in all medical interventions, we must consider the benefits and burdens of the proposed treatment and its alternatives. The benefits of feeding tube placement include giving him a few months longer to interact with the staff and his family. The burdens would include the procedure's risk and the necessity of restraints if the patient attempted to remove the tube. What should guide the medical team and family in weighing the risks and benefits of a feeding tube for Mr. Jackson?

Given the view that benefits and burdens are relative to individuals, some have argued that treatment decisions in patients with dementia should be made with primary attention to their prior expressed wishes. Ronald Dworkin has argued that we should view patients with dementia in the context of their entire life cycle, with the patient's prior expressed wishes being the best expression of his current mentally incapacitated interests. Others, such as Rebecca Dresser, have questioned the psychological continuity of the self from a prior cognitively intact persona to the present demented persona. They argue that prior, cognitively intact preferences for a future demented self may not reflect the new self's will and best interests.

Despite philosophical discussions regarding the "essentialism" of the per-

sona, the notion of “psychological continuity,” and the sanctity of advance directives, few have addressed how one ensures the patient’s best interests. Whether we believe the new demented person is “numerically distinct” from the prior person or an essentially evolved persona in one of life’s many stages, we must recognize the importance of providing care that is beneficent and non-maleficent rather than attending solely to ensuring patient autonomy.

Patient autonomy and self-determination regarding medical care remains and should remain the standard of care. However, situations exist in which physicians, caring for those who can no

## commentary

by Michael Bérubé

The ethical difficulties of Mr. Jackson’s case cannot be resolved by resorting to the ideal of autonomy. This is not because autonomy is a suspect ideal in such cases; rather, it is because this ideal is so ubiquitous that it appears, surreptitiously, even in the arguments of those who critique patient autonomy. In other words, the autonomy that is denied on one plane finds a way of expressing itself on another.

The pervasiveness of the idea of autonomy becomes clearer when we approach it from the perspectives that the idea of disability affords. In her 1994 *Rutgers Law Review* essay, “Missing Persons,” Rebecca Dresser enumerates the reasons courts have an “obsession with autonomy.” After acknowledging how important autonomy is to our culture, she points out that a culture that prizes autonomy is quite likely to regard disability and incompetence as horrors: “Perhaps most powerful of all,” she writes, “is the reaction we have to others who become demented or otherwise cognitively debilitated—God forbid that others would feel this way about us someday!” But one reason Dresser takes issue with “autonomy” is precisely that, in her view, patients are capable of changing their minds about how they would like to live, such that the man who remarks, “Shoot me if I’m ever con-

longer speak for themselves, should depart from a strict autonomy focus to one in which beneficence and nonmaleficence play important roles. Mr. Jackson, if able to communicate, may have stated that his present state is certainly not worse than death. Instead of making a best guess based on Mr. Jackson’s prior wishes, we might consider making decisions based on our and the family’s desire to endow Mr. Jackson’s remaining life with as much quality as possible. Adhering to the principle of “Do No Harm,” and recognizing that a reasonable person might find that the burden of a feeding tube outweighed its benefits, we might have argued against the

fining to a wheelchair,” may decide after a debilitating accident or illness he would rather live with assistance than die on his own.

Dresser primarily critiques positions commonly associated with Ronald Dworkin, but scholars in disability studies have underscored this point many times: when autonomy is the ideal, dependence can only be an aberration or a scandal. The challenge for disability scholars and disability rights advocates has been to convince others that dependency is one of the critical ontological facts of their lives—and not only at life’s beginning and end, but every time we participate in large-scale forms of organization, such as driving on the interstate, taking an elevator, or using the telephone. And yet there are no disability rights groups or disability studies scholars who would advocate more dependency and less autonomy. This ambivalence about autonomy is evident every time disability scholars and activists debate abortion or euthanasia; while groups exist that oppose both in all circumstances that involve persons (or fetuses) with disabilities, many people are nevertheless loath to deny persons with disabilities the right to determine what happens to them.

That ambivalence notwithstanding, the disability perspective has in recent years been aligned with the position that life must be prolonged at all costs. In cases such as *Martin* and *Wendland*, disability-rights groups filed amicus briefs arguing that the wishes of patients

feeding tube, but at least our decision would have deemed important the patient’s current quality of life.

Mr. Jackson was unable to express his preferences. The discussion regarding this difficult decision should not be placed within the context of an autonomy-based model, either by relying solely on the patient’s prior wishes, which may have been based on an incomplete understanding of future health states, or on the shoulders of the family to “pull the plug” based on what the patient would have wanted. Rather, we should focus our discussions on options that promote the patient’s comfort, our presumed goal in this setting.

whose advance directives, like Mr. Jackson’s, indicate that they do not want to be sustained in conditions under which they cannot care for themselves, should be set aside. I have some sympathy with the disability rights argument that some patients’ advance directives reflect the stigma with which able-bodied persons regard disability. Nonetheless, I believe that *Wendland* was wrongly decided, and that decisions such as Mr. Jackson’s should be guided by our best available sense of the patient’s wishes, as well as those of the patient’s immediate family.

When those family members are in conflict, as in *Martin* and *Wendland*, I believe it is better to abide by our best determination of beneficence—inasmuch as this can overlap with the expressed wishes of the patient. Mr. Jackson may have been depressed or hyperbolic when he told his children that he would rather die than live dependently. And he probably enjoyed his family’s and friends’ company even in a state of advanced dementia. But one could imagine him refusing a feeding tube if such assistance would merely prolong his life for a few months, during which he would suffer the effects of head and neck cancer. It is also not unreasonable to accede to his children’s assessments of what his wishes might be, based on their knowledge of him over the course of his and their lives. In withholding the feeding tube and intravenous fluids, the medical team very likely respected his autonomy—and his human dignity.

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