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Voice: Cognitive Impairment and Medical Decision Making

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On a leafy, sun-dappled front porch in a suburb of Washington, D.C., are two women. The younger woman is not young; she is tiny, silver-haired, and 65. Her mother is there, too, and she is even tinier, far more frail, and 97 years old. The mother is severely demented, and has not spoken a word for several years. She lives here, in the modest split-level home she has owned for many years, with a home attendant. Her daughter visits daily. The daughter has taken advantage of this warm, early spring day to settle her mother comfortably in the sun, outside on her porch, where she has not been for many months. The daughter tucks an afghan blanket carefully around her mother's legs. The mother knit this blanket herself in cheerful colors and happier times, many years ago. Seeing her mother so nicely settled, and proud of her efforts at taking such good care of her, the daughter says, "There, Mother. How is that?" The mother looks her daughter straight in the eyes. Her face is struggling. She makes a sound; she is trying to speak. At last the mother produces a single word, said with clarity and fierce intensity. She says, "Lousy."

This word was my grandmother's last. It came in the last year of the long life of Mercedes Phelan Hayden, a life that was full of many events and satisfactions. The word was spoken to my mother, and it is unlikely it would have been spoken at all but for the presence of my mother, there with her mother on that day. It cost something for my grandmother to summon the strength to say her word; it surely cost something for my mother to hear it. An isolated word, after years of silence, takes on depth. Language can be like a broth, simmering for years, reducing and condensing into sharper and deeper flavor with every day that passes, until finally there is just the one word that stands for all that has happened and that has needed saying. The word could have meant that my grandmother didn't like sitting in the sun on her porch that one day, but my mother took it to have wider implications. My mother took the word as a summary of the experience of being demented, 97, and no longer ever comfortable, not even on the best days.

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The sweep of developments in bioethics and the law of the last decades has led to an increase in autonomy in medical decision making, but only for the privileged few. Patients who retain decision-making capacity, or those who clearly recorded their wishes when they had capacity, have gained a greater role in shaping their medical care than was previously available. For those who always lacked capacity, or who lack it now and failed to comment on their wishes when they might have, the developments of recent decades are less benign. The vast majority of patients who now lack capacity have not provided properly executed

advance directives indicating their wishes for medical care. The focus on individual autonomy in law and bioethics has failed to improve medical decision making on behalf of this majority of incapacitated patients.

Bioethics must look to new ways to acknowledge and respect the experience of those who lack decision-making capacity. For decision making to be truly ethical for those without capacity, we must find a middle ground between the full-scale autonomy of those with capacity and the abnegation of current participation by those who lack capacity. For the severely cognitively impaired, significant medical decisions must still be made by concerned others. However, those others should be guided by their knowledge of the impaired person's experience, either pleasurable or painful, by the expressions of this person's will and by other factors that I will refer to as the "voice" of the incapacitated person. Voice may refer to literal speech or its remnants, as in the case of my grandmother, or it may refer to nonverbal acts of attempted communication. Voice may also, for those most severely impaired, come down to our efforts to understand the experience of the cognitively impaired person whose ability to communicate may be vestigial. In these cases, the voice of the cognitively impaired is heard only through the empathic efforts of one who seeks to appreciate the experience of the injured person. An emphasis on voice, which in turn relies upon empathic communication, will support a robust role for surrogate decision making by family members, as opposed to legally appointed strangers and the courts.

AUTONOMY RISING

As stated famously by Justice Benjamin Cardozo, "Every human being of adult years and sound mind has a right to determine what shall be done with his own body."¹ However, the right to medical self-determination was not established by Cardozo's landmark opinion; it took many years, further legal decisions, and considerable public debate to secure a measure of reliability for the right of those with sound minds to determine their medical care.

The efforts of Dax Cowart were significant in the struggle to permit patients with decision-making capacity to exercise their rights to make controversial medical decisions, and in particular to refuse medical treatment. Cowart was a robustly healthy young man who was severely burned in an explosion in the 1970s. Cowart survived the explosion and fire, but the treatment for his burns was excruciating, as captured in the widely known documentary, *Dax's Case*.² Interviews with Cowart, his family, his physicians, and others confirm his superlative cognitive capacity, yet his voice and well-articulated refusal of treatment were ignored. Cowart survived to build a life he found meaningful; blind and with some other physical disabilities, he attended law school, married, and successfully pursued other professional and personal goals. However, he has argued forcefully that only he suffered the pain of his rehabilitative surgeries and other treatments, and that only he, given his cognitive capacity, should have had the right to determine whether the possible benefit of a fulfilling future life outweighed the immediate pain of his symptoms and their treatments. Such an abrogation of a capable patient's decision-making rights would be far less likely in the U.S. today, in part because of Cowart's crusading efforts. Moreover, the far greater attention today to pain control might have permitted Cowart to attain the benefits of rehabilitation without such an extraordinary burden of suffering.

THE VOICELESS PATIENT

Gains in the freedom of cognitively intact patients to reject unwanted treatment are important and positive. Unfortunately, decision making for the cognitively impaired has not evolved to the same extent. In particular, the voice of cognitively impaired patients has been harder to incorporate into medical decision making and the law. Nowhere has the absence of voice for the cognitively impaired been more obvious than in New York State.

New York courts addressed surrogate decision making in 1981 on behalf of John Storar, a 52-year-old severely retarded man with terminal bladder cancer.³ Storar's medical situation, although familiar to many, bears review. Storar was born in the 1920s and was institutionalized, as was common for children with his

level of severe retardation. His cognitive abilities in adulthood were described as comparable to those of an 18-month-old. In practical terms this meant that Storar could walk, could communicate in a rudimentary fashion, and was not capable of higher order thinking. Throughout his years of institutionalization, his mother visited him virtually daily; her standing as a loving parent was unquestioned throughout the ensuing legal case.

In July 1979, John Storar was diagnosed with bladder cancer. His mother, wishing for him to receive appropriate curative treatment, obtained legal status as his guardian for the express purpose of agreeing to radiation therapy and transfer to a hospital that performed the necessary treatment. After these radiation treatments, Storar's cancer went into remission for eight months, but recurred in March of 1980, when he also developed hematuria. His physicians made various attempts to curb his recurrent bleeding through cauterization, also agreed to by Storar's mother, but these attempts proved unsuccessful. Storar continued to lose blood, and his anemia was treated by transfusion. Alas, transfusion is not as straightforward for a terminally ill, severely retarded man as it might be for another. Storar's transfusions required that he remain still without disturbing an intravenous infusion for hours at a time. He was incapable of understanding the reason for this treatment, and was unable to comply voluntarily with the restrictions on his movements. To receive transfusions, Storar was physically restrained and given sedatives. Storar was anxious during the treatment as well as afterward, since transfusion was often followed by the appearance of large blood clots in his urine. Storar's cancer was widely metastasized, causing him considerable pain. In addition to the pain of his illness, he was also forced to endure the pain and fear of his treatment "because of the force that compelled him to submit"; the result was that he became withdrawn, keeping to his room far more than previously.⁴ Unlucky Storar; his medical treatment undermined his limited ability to communicate with others while he was dying and most in need of comfort.

Mrs. Storar grew distressed by the effect of the transfusions on her son and sought to stop them, stating that they served "only to prolong his discomfort."⁵ The hospital refused and went to court to get permission to transfuse Storar over the objections of his legal guardian, his mother. At a hearing in September, his physicians noted that Storar had entered the terminal phase of his illness, that is, that his cancer had widely metastasized, and that he was likely to live another two and six months, even with transfusions. The case wound its way through the New York judicial system, and the final decision was handed down in March 1981. Storar was dead by then, having received transfusions to the last. The decision supported the right of the physicians to transfuse Storar over the objections of his mother.

Much has been written about Storar and the decision by Judge Sol Wachtler, then New York's highest judge. The case has been alternatively viewed as a defeat for those who support the right to die and as a victory for those who support the right to full treatment for the disabled.⁶ What the Storar case does most effectively, however, is to illustrate the lack of John Storar's voice in the decision made for him, and the suffering that ensues from ignoring that voice.

Wachtler did attempt to assess the best interest of Storar, but he did so in a way that ignored Storar's individual experience. Wachtler noted that Storar's mental capacity was that of an "infant," and that therefore his rights would be evaluated like those of other infants. Wachtler compared Storar's case to that of transfusion cases involving infants of Jehovah's Witness parents, and found that, in these cases, the benefits of transfusion clearly outweighed the burden. If Storar were an otherwise healthy infant requiring a transfusion, Wachtler's reasoning might be compelling. However, Storar's circumstances differed from those in the cited cases in crucial details. Storar was not like an 18-month-old with a treatable illness; he was in fact a 52-year-old man dying of cancer. Although most other patients do not experience transfusions as painful, Storar required physical restraint and sedation. For Storar, transfusion imposed a burden of fear that made these treatments comparable to a treatment that would be far more invasive for most patients. Moreover, Storar was terminally ill, and all parties agreed that these treatments would at most only briefly prolong his life.

Wachtler's decision reflects a failure of empathy; he does not attend to the voice of Storar. To say that Wachtler lacks empathy for Storar does not suggest that Wachtler is cruel or even indifferent to Storar. On the contrary, Wachtler tries to do what he believes is in Storar's best interest. However, the information he uses

to determine that best interest does not depend on empathic knowledge of Storar's condition, but entirely excludes it. Wachtler therefore does not succeed in making a decision that corresponds to Storar's actual circumstances. For Wachtler, Storar becomes a sort of human widget, an ageless, featureless, nonspecific entity. If Storar were like a healthy baby with a curable disease, or like a capable adult who comprehended the purpose of transfusion, the decision might have corresponded to Storar's situation. As it was, the decision did not fit the circumstances of the specific individual who was John Storar.

In *Storar*, the court nominated itself to the role of decision maker, although Judge Jones, in his dissent, stated a decided preference for the family. In his dissent, Judge Jones noted that Storar's "mother over his lifetime had come to know his wants and needs and was acutely sensitive to his best interests; that she had provided more love, personal care, and affection for John than any other person or institution, and was closer to feeling what John was feeling than anyone else."⁷ The dissenting judge thus privileges the role of Mrs. Storar in interpreting her son's communications and experience. Judge Jones goes so far as to say that he doubts that courts have, in general, a useful role to play in surrogate decision making. Rather, Judge Jones notes that there is "no empirical evidence that either society or its individual members have suffered significantly in consequence of the absence of active judicial oversight."⁸ Nor would Judge Jones recognize the standing of the medical facility to seek judicial authority to continue transfusions over the objection of Mrs. Storar, finding the interests of the medical providers "tangential" in comparison to those of the patient and family. Had Jones's decision stood instead of that of the majority, it would have radically altered the process of surrogate decision making in New York and perhaps nationally. Such a decision would have invited greater attention to the role of families and of empathy in decision making for incapacitated patients.

EMPATHY IN MEDICAL DECISION MAKING

Jodi Halpern, in *From Detached Concern to Empathy*, calls for the greater use of empathy in a somewhat different context, that is, she focuses on the use of empathy by physicians.⁹ Halpern offers a "skeptical questioning of the norm of detached concern" for physicians, and instead suggests that retaining the capacity to be moved by patients is a crucial part of being an effective healer.¹⁰ Our focus here is not to examine the use of empathy by doctors, but rather to draw a parallel to decision making on behalf of impaired patients by judges, who also favor detachment over emotionally connected reasoning. Halpern provides a defense of empathy, which she describes as an emotional and experiential comprehension of the situation of another, as opposed to a form of knowing that comes through purely theoretical and intellectual reasoning.¹¹

To accept that empathy has an appropriate role in decision making for others, one must first agree that emotion, upon which empathy depends, can contribute to the process of reasoning. Halpern reviews the work of the many philosophers and other scholars who denigrate the use of emotion in decision making. She cites Descartes's argument that, since emotions can be spontaneous and automatic, they must therefore be irrational and not subject to revision by the processes of reason.¹² Kant also devalued the role of emotions, arguing that only by detaching reason from emotions and social influences can one generate the sort of thought that constitutes the exercise of autonomy.¹³

Halpern, however, refutes this bias against the use of emotion in reasoned decision making. She draws upon the work of contemporary philosophers like Bernard Williams to illustrate the limits of Kant's emphasis on reason in the absence of emotion.¹⁴ As an example of autonomy, Kant described the case of a suicidal man deciding whether or not to end his life. For Kant, the man will choose to live if he exercises his reason and finds that he cannot support the notion of a universal maxim that permits one to commit suicide when there is no longer a reason to live. Halpern, a psychiatrist and a philosopher, is well aware that this is not the sort of thinking that generally helps desperate people refrain from suicide. However, even if a person did reject suicide based on purely detached reason, this act would not, for Halpern, constitute an expression of autonomy. For Halpern, "the capacity to make use of detached reason to commit to impersonal goals" is not enough to produce autonomous decisions.¹⁵ Fully autonomous reasoning requires that an individual generate goals with personal meaning. In the example of the suicidal man, deducing a universal maxim neither fully

expresses his autonomy nor provides sufficient motivation to tolerate the continuation of a painful life.

It is interesting that accounts exist of the mental processes that suicidal persons actually use to find a reason to continue living. One such account occurs in *Undercurrents: A Life Beneath the Surface*, psychologist Martha Manning's narrative of her descent into and recovery from suicidal depression.¹⁶ Manning confesses to her psychiatrist that she contemplates suicide and he asks, "What stops you?" Referring to her only child, she replies, "Keara, I can't leave Keara. . . . She is the only thing that stands between me and dying."¹⁷ Manning's irreplaceable obligations as a mother demand that she tolerate her present pain to raise a beloved daughter; she finds her reason for being within her family, in the emotional bond to her daughter. That Manning's choice is suffused with emotion makes it no less a reasoned moral choice, and a painful one. This sort of choice requires a person to make a life and death decision by reflecting not only upon critical values, but also by weighing the full emotional consequences to the self and to valued others. This choice, more than an abstract, purely rational choice, more closely reflects the sort of autonomous choice that is relevant to medical decision making.

Manning is a capable decision maker, despite her depression, and she withstands the pain of depression long enough to find an effective treatment (electroconvulsive therapy in her case) and regain a life she enjoys living. But how are we to imagine a form of surrogate decision making that would similarly permit the use of emotionally laden information on behalf of the incapable patient? Judge Jones, in his dissent in *Storar*, seems to be arguing for just such a system when he questions both the role of the courts as decision makers and the standing of healthcare providers to question the decision of a parent on behalf of the adult child for whom she has cared for decades. Jones relies upon the interpretation of one who has an intimate relationship with the incapacitated patient. He privileges information derived from that relationship above the knowledge accrued by professional training for either judges or physicians.

SURROGATE DECISION MAKING: WHO VERSUS WHAT

The battle over surrogate decision making has raged for more than 25 years. No sooner is victory declared than a fresh skirmish breaks out, and the illusion of consensus is once again destroyed. The recent *Schiavo*¹⁸ case is but one more example in a chain stretching back to *Quinlan*,¹⁹ and including *Storar*, *Cruzan*,²⁰ and a host of other legal cases. The distinction between *who* makes surrogate decisions versus *what* decisions are made has been a key theme in this saga. Commentators with strong opinions about *what* is decided are willing to subjugate the decision-making authority of various groups; those who favor process over outcome insist on determining the right answer to *who* should decide and must accept a wider range of decisions about *what* is decided.

The argument over who should make surrogate decisions can be resolved in favor of families, courts, specific types of surrogates, or some combination of these three. In *Storar*, the court nominated itself to the role of decision maker, although one judge dissented, stating a decided preference for the family. The bioethics literature has addressed this topic exhaustively; many commentators uphold the family as the proper decision maker. For instance, the President's Commission report on end-of-life care argues that the family should be the presumptive surrogate for the incapacitated patient.²¹ The President's Commission recommends that the family be thus privileged for various reasons, including:

- The family is most interested in the patient's well-being;
- The family is "most knowledgeable" about what the patient would choose;
- The family's important and long-standing social role as caretaker for its members should be recognized;
- Families require privacy to flourish, and the state "should be reluctant to intrude" upon such personal matters.²²

Although many authors agreed with the preference for family decision makers expressed by the President's Commission, not all did. Ezekiel Emanuel, for instance, strongly criticizes the fitness of families as surrogate decision makers.²³ He argues that it is not always easy to determine who forms part of a patient's family,

as families are currently defined. He cites compelling evidence that family members are not well-informed about each other's preferences,²⁴ and notes that they may also disagree with one another about the incapacitated patient's wishes. Moreover, family members may know the patient's preferences and choose to ignore them.

Emanuel is surely correct that families exhibit many flaws as surrogate decision makers. His proposed solution, however, hardly represents an attractive alternative. Emanuel suggests that the delegation of surrogate decision-making authority to families reflects society's inability to wrestle with the difficult choice of *what* should be decided on behalf of incapacitated patients. He prefers a system in which communities articulate their values and accompanying medical choices. "Citizen-members" of various health plans would examine their beliefs and options, allowing them to reach a consensus about the appropriate treatment for a given situation.²⁵ For instance, within a given health plan, all or no patients in a persistent vegetative state (PVS) might receive artificial nutrition and hydration, depending on this community's vision of the good life.

Events during the decade since Emanuel proposed his model of decision making by "citizen-members" of health plans do not support the notion that communities would successfully reach consensus about end-of-life treatment decisions. Americans hold widely varied and passionately defended notions of when treatment must and must not continue for incapacitated patients. Those who did not concur with the policies of an Emanuel-style health plan would be forced to find care elsewhere. For urban dwellers, this might be possible, although inconvenient. For Americans in rural areas, where healthcare facilities are fewer, Emanuel's system might create the medical equivalent of the partitioning of India, with like-minded citizens moving en masse from one section of the country to another. Emanuel finds fault with the family as surrogate decision maker, but, in its stead, offers a system that is unworkable on two accounts. First, as a practical matter, communities are unlikely to attain the necessary degree of consensus on contested end-of-life treatments. Second, if the system did exist, it would create unacceptable levels of dislocation and anguish in the healthcare system.

Rebecca Dresser, in "Relitigating Life and Death," also rejects the family as surrogate decision maker.²⁶ Dresser stresses the importance of the incapacitated patient's current interests, and argues that neither the family's views of the patient's interests, nor even the patient's own statements expressed when competent, should take precedence over those interests. Dresser assigns to the courts the weighty task of determining just what the patient's current interests might be. Dresser acknowledges that her proposal would vitiate the effect of a living will or other advance directive, and she accepts that outcome. She would have the courts mandate treatment that they determine is in the patient's interests, and forbid treatment that is not, regardless of the family's opinion or the patient's own advance directive. Dresser elevates the importance of the current experience of the incapacitated patient, but she offers no reasonable means to understand the particularities of that experience. Once again, the incapacitated patient is a voiceless everyman, a human widget who is interchangeable with any other patient with the same diagnosis. This style of decision making turns its back on the role of empathy in caring for incapacitated patients.

Like Emanuel, Dresser believes it is possible to find a "right" answer for a treatment decision for a specific person without consulting his or her family. However, Emanuel would find that answer through an open political process akin to Jeffersonian democracy, while Dresser would let judges choose the "objectively" correct answer — without any semblance of consensus building. In both cases, the decision-making authority of the family is transferred to strangers who have no connection to the incapacitated patient, and who have no track record that might suggest they would make better decisions.

FAMILY DECISION MAKING

Both Emanuel and Dresser correctly note that families have an imperfect track record on making wise decisions, or even ones that reflect the wishes and interests of the patient. In contrast, Hilde Lindemann and James Lindemann Nelson acknowledge those flaws, yet still insist on the importance of family as interpreter

for the incapacitated patient.²⁷ In their book, *The Patient in the Family*, Lindemann and Lindemann Nelson describe, among other things, the roles and values that families maintain. Familiar tasks taken on by families include those of protecting, nurturing, and socializing not only children, but all members of the family. In addition to these functions, Lindemann and Lindemann Nelson examine the role of the family in forming an individual's identity. The history of the family intertwines with that of the individual. This mutually developed narrative contributes "both to our sense of who we are and to our sense of why it matters who we are."²⁸

Families do not rely solely upon abstract principles when they make decisions on behalf of an incapacitated member. In contrast to other ethical systems that value impartiality, a family's ethical obligations require a focus on a particular individual. Family decision making may entail a search for equal justice between members, such as when apportioning goods and privileges among siblings, but that justice will require knowing the specific circumstances of the family members, and the valuation that the particular members assign to the goods and privileges under consideration. It is not equal justice to put both the three-year-old and the 17-year-old to bed at 8 p.m., nor to allow each to drive the family car one night per weekend. But family members do not only have factual information about each other. They are uniquely qualified to supply the emotional knowledge about patients upon which empathy depends, and which is so crucial for making a surrogate medical decision.

Lindemann and Lindemann Nelson note a number of guiding principles that capture the ethics of families. Among these "stars to steer by" is the notion that "family members aren't replaceable by . . . better qualified people."²⁹ This principle has important implications for the role of families in surrogate decision making. To take an example, suppose that in the course of your life you mourn the loss of a loved one. Your friend, whose first language is not English, sends you a letter of condolence that is genuinely comforting, despite a number of lapses in spelling and grammar. What matters to you, and what makes this gesture meaningful, is not that this is the best possible letter. For that, you might wish to review condolence letters by great authors of the past, such as Abraham Lincoln. What gives this letter meaning is that a specific person who cares about you took some trouble, perhaps a great deal of trouble since English is not easy for her and the letter is specifically for you, in your present difficulty. It is the act of caring that matters. This example involves a friend rather than a family member, but it is by similar acts of caring that families maintain bonds. Lindemann and Lindemann Nelson argue compellingly that it is for this reason that families have a meaningful role as surrogate decision makers in medicine. It is not that families necessarily know best what to do; the value of a decision made by family is that it is made by a specific person or persons who matter to the patient and to whom the patient matters. To the family, the patient is a person, not a widget, in a way that can never be true for the impartial decision maker, who is to this person a judge, physician, or other neutral yet anonymous professional. The form of knowledge that makes this person unique cannot be derived in the abstract, but grows from lived relationships between people.

Numerous authors have attempted to describe ethical systems that are based on caring. Joan Tronto, in *Moral Boundaries*, describes four phases of caring.³⁰ In the first phase, "caring about," a need is noted and recognized as such; this phase includes noting the plight of another, for instance a homeless person. Next, in "taking care," the one who has observed the need accepts responsibility for it. This phase might include voting in a way that will support improved services, or donating money to a charity that addresses the identified problem. Tronto's third phase is called "care giving," and involves directly meeting a need for care. This phase generally requires physical work and person-to-person contact for the caregiver; one example would be the adult daughter who takes a leave of absence from work to care for a dying parent. The fourth phase is that of "care receiving," since the recipient shares in the process in important ways. The capacity to give thanks and to offer reciprocal caregiving shape the meaning of receiving care for both giver and receiver. Tronto, focusing on the political context of caring, notes that these four phases interact with gender, race, and class. The first two phases, which can be accomplished with money and influence, generally are duties of those with power in contemporary society. Those with less power are far more frequently involved with the second two phases, caregiving and receiving.

By Tronto's system, the assignment of decision-making authority to the courts corresponds to keeping

that authority in the hands of those who already have a disproportionate share of societal power, and who never deliver the actual care to those in need. In contrast, relying on the family as first choice for making surrogate medical decisions acknowledges the family's role in providing care in a direct way and over time. This power will rely less on societal status and more on the knowledge that particularizes the needs of this incapacitated patient. Relying on the family as default surrogate decision makers keeps these decisions closer to the people who will provide and supervise the actual care, and who are thus in a better situation to observe the ethical dimensions and outcome of their choices.

VOICE

The ability to appreciate the voice of the incapacitated patient decreases with emotional distance and increases with intimacy. Family members may not bring optimal levels of empathy to every encounter with cognitively impaired relatives, but they are better situated for empathic communication than judges, who often never see the person whose life is determined by their decisions. A patient's physician may have an ongoing relationship and a clearer sense of the patient's circumstances, but is less likely in general than a family member to have a sustained emotional relationship with the severely impaired patient.

Empathic connection can amplify the impaired person's ability to communicate, as may have happened when my grandmother last spoke to my mother. The incapacitated patient may be moved to reach out to someone who is listening; the attentive listener is more likely to perceive an effort to communicate. When impaired patients can communicate, empathy enhances the signal and permits decision makers to incorporate this information.

Knowledge that is gained through empathic communication increases our ability to understand the patient's wishes and preferences. The focus here is exclusively on patients who lack decision-making capacity; the preferences of these patients cannot solely determine medical decisions made on their behalf. Current practices often exclude entirely the experiences and communications of the impaired patient, and that seems as wrong as letting an impaired patient make a choice without the requisite capacity. Attention to the voice of the incapacitated person permits others to make decisions that reflect the needs and circumstances of this specific, loved individual. When communication is no longer possible, a family member's intimate, sustained relationship allows decisions to be made in the best interest of that person. This version of best interest does not rely upon a generic definition that is applicable to anyone who might appear to be similarly situated "on paper," but relies on the interests of *this* person, seen in intimate detail.

Attention to the voice of cognitively impaired patients offers us two ways of improving decisions on their behalf. We can use empathic knowledge to draw out the patient's ability to communicate preferences, and factor that information into decision making. We can also use empathic knowledge to determine the best interests of this unique and valued person, and make medical decisions that are shaped by such intimate knowledge.

CONCLUSION

Sadly, anyone may cite instances of families in which members appear to know or care little for each other's deeply held personal values. Even in caring families, casual acquaintances may sometimes know what family members do not. A spouse may be the last to know of a partner's infidelity or alcohol addiction; parents may not know their son is gay although his siblings and friends do. Worse still, family members may intentionally place their own interests ahead of those of the incapacitated patient.³¹ Other families may correctly reflect a patient's wishes, but insist upon treatment that physicians and facilities find is inappropriate; these families may need limits on the treatment they can request. Family members may disagree with one another about a surrogate decision. These families should be offered mediation so that they may reach agreement, but some may force the courts to serve as the final arbiter. Finally, some patients lack family altogether, and assigned professionals will inevitably make decisions on their behalf.

Nonetheless, families should serve, whenever possible, as the surrogate decision maker for patients who did not or could not express their medical preferences. Knowledge that is earned by living with and caring for another person, that is suffused with time and shared emotional experience, is the form of knowledge that is demanded for making medical decisions on behalf of another. The family provides history, identity, and cultural and ethnic specificity in a way that impartial decision makers cannot. The family can see the patient over time and in different roles. A single word, spoken to someone who can hear it in the fullness of its meaning, can speak volumes. Imperfect as they are, families still serve as the best source of information that distinguishes this person from all others. Medical decisions cannot be made on a generic basis, but they affect a specific person, and should reflect the circumstances of that person. To borrow from Winston Churchill, families are the worst solution for making surrogate medical decisions, except all other systems that have been tried.³²

DISCLAIMER

The views expressed are solely those of the author and do not reflect the opinion of the New York State Task Force on Life & the Law nor of the government of the State of New York.

NOTES

1. *Schloendorff v. Society of New York Hospital* (1914) 105 N.E. 92, 92-94.
2. *Dax's Case: Who Should Decide?* VHS (New York: Unicorn Media for Concern for Dying, 1985); see also, E.A. Rosenberg and D.A. Karides, "An Interview with Dax Cowart," *Journal of the American Medical Association* 272, no. 9 (1994): 744-5.
3. *In the Matter of John Storar* (1981) 420 N.E. 2d 64; 52 N.Y. 2d 363.
4. *Ibid.*, 280.
5. *Ibid.*, 260.
6. G. Annas, "Help from the Dead: The Cases of Brother Fox and John Storar," *Hastings Center Report* (June 1981): 19-20; A. Asch, "Disability, Bioethics, and Human Rights," in *Handbook of Disability Studies*, ed. G. A. Albrecht, K. D. Seelman, and M. Bury (Thousand Oaks, Calif.: Sage, 2001).
7. See note 3 above, p. 281.
8. *Ibid.*, 278.
9. J. Halpern, *From Detached Concern to Empathy: Humanizing Medical Practice* (New York: Oxford University Press, 2001).
10. *Ibid.*, xvi.
11. *Ibid.*, 72, 75.
12. *Ibid.*, 45.
13. *Ibid.*, 108.
14. *Ibid.*, 110.
15. *Ibid.*, 111.
16. M. Manning, *Undercurrents: A Life Beneath the Surface* (New York: HarperCollins, 1995).
17. *Ibid.*, 105.
18. *In re Guardianship of Schiavo*, 800 So. 2d 640 (Fla. 2d Dist. Ct. App. 2001).
19. *In re Quinlan*, 70 N.J. 10, 355 A.2d 647 (1976).
20. *Cruzan v. Director, Missouri Department of Health*, 497 U.S. 261 (1990).
21. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Deciding to Forego Life-Sustaining Treatment* (Washington, D.C.: U.S. Government Printing Office, 1983), 127-9.
22. *Ibid.*, 128.

23. E.J. Emanuel, *The Ends of Human Life: Medical Ethics in a Liberal Polity* (Cambridge, Mass.: Harvard University Press, 1991).
24. *Ibid.*, 56-7.
25. *Ibid.*, 178-80.
26. R. Dresser, "Relitigating Life and Death," *Ohio State Law Journal* 51 (1990): 425-37.
27. H.L. Nelson and J.L. Nelson, *The Patient in the Family: An Ethics of Medicine and Families* (New York: Routledge, 1995). Hilde (Lindemann coauthored this book as H.L. Nelson.)
28. *Ibid.*, 42.
29. *Ibid.*, 74.
30. J. Tronto, *Moral Boundaries: A Political Argument for an Ethic of Care* (New York: Routledge, 1993).
31. J. Hardwig, "The Problem of Proxies with Interests of Their Own: Toward a Better Theory of Proxy Decisions," *The Journal of Clinical Ethics* 4, no. 4 (Winter 1993): 20-7.
32. W. Churchill, "Speech in the House of Commons," 11 November 1947. Churchill stated, "democracy is the worst form of government except all those other forms that have been tried from time to time."