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Incapacitated Surrogates: A New and Increasing Dilemma in Hospital Care

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ABSTRACT

A power of attorney for healthcare (POAHC) form gives designated individuals legal status to make healthcare decisions when patients are unable to convey their decisions to medical staff. Completion of a POAHC form is crucial in the provision of comprehensive healthcare, since it helps to ensure that patients' interests, values, and preferences are represented in decisions about their medical treatment. Because increasing numbers of people suffer from debilitating illness and cognitive deficits, healthcare systems may be called upon to navigate the complexities of patients' care without clear directives from the patients themselves. Hence, the healthcare industry encourages all individuals to complete a POAHC form to ensure that persons who have the patients' trust are able to act as their surrogate decision makers. However, sometimes POAHC agents, even when they are patients' trusted agents, lack the capacity to make fully informed decisions that are in the patients' best interests. We describe designated surrogate decision makers who have impaired or diminished judgment capacity as *incapacitated surrogates*. Decision making that

is obviously flawed or questionable is a significant impediment to providing timely and appropriate care to patients. Moreover, failure to redress these issues in a timely and efficient manner can result in significant costs to an institution and a diminished quality of patient care. The authors offer a legal, ethical, and interdisciplinary framework to help navigate cases of incapacitated surrogates.

INTRODUCTION

Despite two decades of concerted effort by the healthcare industry, a majority of hospitalized patients with serious illness have no documented advance directive. An advance directive can voice patients' decisions on important healthcare decisions and designate and empower surrogate decision makers (also called agents) by completing a power of attorney for healthcare (POAHC) form. Agents named in patients' POAHC forms make decisions and carry out patients' healthcare choices when patients become incapacitated. Studies report, however, that POAHC agents often fail to make the decisions that are indicated by patients' previously stated preferences.¹ Some healthcare professionals question the adequacy of specifying only one POAHC agent, although it is common practice to designate only one primary surrogate decision maker.² Our aim is not to address process standards with regard to POAHC agents. We offer a framework that members of ethics committees and other medi-

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cal staff may utilize when they question the decision-making capacity of a POAHC agent.

Given the growing number of persons living into very old age and the increasing numbers of persons suffering from Alzheimer's disease and other cognitive deficits, designated POAHC agents are more likely to have medical conditions that impede their decision-making capacity. Furthermore, healthcare teams may struggle with the impairment of POAHC agents due to the agents' psychological issues, substance abuse, mental illness, conflicts of interest, or replacement of their own personal values and judgments for those of patients.³ A number of ethical and legal issues are involved when an agent's capacity is faulty or questionable. Central issues are whether surrogates' decisions represents the patients' best interests, and not the interests of surrogates, and whether decisions that are made by surrogates are fully informed, reasonable choices.

When issues of incapacitated surrogates arise, the healthcare system has limited options to remove surrogates. Failure to effectively manage these situations can result in poor outcomes for patient care and excessive burdens for the healthcare system. Instead, care teams must look for ways that are systematic, fair, and justifiable to evaluate those whose decision making we question while teams continue to provide optimum patient care. This article details two cases in which the capacity of surrogates was in doubt because they made questionable decisions or went against the stated preferences of the patients. The focus is on the reliability of the surrogates' decisions and on the hospital's responses. The authors offer a framework to identify and clarify issues to facilitate healthcare providers' navigation of potentially complex ethical and legal situations involving incapacitated surrogates. Specifically we aim to identify a threshold for when it is appropriate to pursue legal channels to remove POAHC agents.

CASE PRESENTATIONS

The Case of Mr. M

Mr. M was a 66-year-old man diagnosed with Alzheimer's disease and chronic dysphagia (difficulty swallowing) who exhibited an altered mental status when his brother brought him to the emergency department from a subacute rehabilitation facility (SAR). Evaluation at admission noted that Mr. M suffered from dementia with superimposed mixed-type delirium. He was treated with intravenous (IV) antibiotics for aspiration pneumonia. Mr. M was severely malnourished and his mental status

fluctuated from unresponsive to severely confused, with agitation and nonsensical speech. Mr. M failed a video swallow evaluation and multiple bedside swallow evaluations. Meetings with Mr. M's only involved family member and POAHC agent, his brother, Mr. D, included the palliative care consultation team, a registered nurse (RN), case management, and rehabilitation services, and discussed artificial nutrition and placement of a PEG (percutaneous endoscopic gastrostomy) tube. After these discussions, Mr. D consented to placement of a PEG tube and initiation of artificial nutrition.

Mr. D attended all family meetings with the care team. His beliefs about his brother's condition, however, were inconsistent with the medical diagnosis. That is, Mr. D believed that Mr. M's acute mental status change, overall decline in cognition and functional status, and dysphagia were due to the patient's being out of his home environment. Mr. D insisted that Mr. M would "snap out of it" and return to baseline if he was allowed to return home. Mr. D did not change his point of view, even after attempts to educate him about the patient's medical condition, the nonreversible decline of dementia, the cause of cognitive and functional decline, and the patient's dysphagia.

During the course of family meetings, the care team became concerned that Mr. D's denial of Mr. M's condition was not due to ineffective coping with the potential loss of his brother, but an inability to understand, remember, and process information. Questions about Mr. D's decisional capacity prompted further concerns that the patient would not be properly cared for at home. For example, Mr. D talked about placing the patient, who was quite emaciated, on a hardwood floor to sleep because Mr. M had preferred sleeping on the floor, rather than on a mattress, in his younger, healthier days. Furthermore, Mr. D described wanting to give the patient his favorite foods as a way to help him recover. The team became increasingly concerned about Mr. D's attempts to feed the patient solid food when the patient clearly demonstrated aspiration on all consistencies of a modified diet. Attempts to discuss these concerns with Mr. D led to his insistence that sleeping on the floor and eating his favorite foods was what his brother needed.

Given these concerns and the patient's overall functional impairment, the medical team felt that a skilled nursing facility would be the most appropriate option for Mr. M, but Mr. D felt very strongly that he was responsible for the patient and needed to care for him at home. He stated that several generations of his family had cared for elderly loved

ones with complex needs within the home. Mr. D felt that it was his duty to care for his brother and this was the only way that he would recover.

The in-patient team expressed concerns about discharging Mr. M to the care of his brother when it was clear that the brother did not fully understand Mr. M's condition. The team believed that the patient would be at risk of harm.

Legal counsel and risk management were consulted for advice on discharging the patient to a potentially unsafe environment. Despite Mr. D's unwillingness or inability to understand his brother's medical condition, he was open to learning new skills to care for his brother at home and appeared to have his brother's best interests at heart. Furthermore, the hospital could not require Mr. D to submit to a formal capacity evaluation to determine whether he was capable of making appropriate medical decisions for the patient. Taking action to prevent the patient's discharge to his brother would have obligated the hospital to pursue costly measures for alternative guardianship, further delaying his discharge and putting him at risk for hospital-acquired complications.

The care team was advised that, in the absence of overwhelming evidence that Mr. D could not adequately care for his brother, the organization's obligation was to teach Mr. D the necessary skills to care for his brother, set up home services for him, and document their concerns and the education that had been provided to Mr. D. The patient was eventually discharged to his home with his brother and home care services.

The Case of Mrs. P

This case involved an 82-year-old woman, Mrs. P, who was admitted to the intensive care unit (ICU) with acute chronic congestive heart failure, acute renal failure, and respiratory failure. This admission came three days following her previous discharge from a 36-day hospital stay. Prior to intubation, in a documented conversation with an RN, Mrs. P stated that she would agree to intubation but did not want it to continue to the point of requiring a tracheostomy. No other family was present. Mrs. P had her POAHC activated⁴ when intubation was approaching two weeks and important decisions needed to be made. It was apparent that a tracheostomy was needed to continue treatment, or a decision was needed to follow Mrs. P's wishes and remove her from life support. Further, if Mrs. P's aggressive treatment continued, it would require her transfer to a long-term acute care facility (LTACH) or a nursing home where she could be on a ventilator for long-

term care. Mrs. P's POAHC form was closely looked at by the care team. Her husband was listed as the first agent, but he voluntarily deferred to his son, Tom, the second agent. A third agent was listed, Mrs. S, the patient's sister-in-law. It was later learned that the husband had had a dementia diagnosis for more than two years. Tom was Mrs. P's only child, and lived in California. Tom sent his wife to assist in his father's care and to oversee his mother's hospital stay while he was working in California. Tom was often unavailable for arranged phone conferences with medical staff and seemed to focus on irrelevant issues. Early in his mother's treatment, he demanded that the hospital administration provide documentation that seemed to have little to do with his mother's well-being. For example, he requested the names of the people at her insurance company who had been contacted regarding his mother's care, and *exactly* what information had been shared. The son issued veiled threats of litigation and informed staff that he worked in a law office. When Tom did come to see his mother, he had poor social interaction skills and poor personal hygiene and demonstrated paranoid thinking. He exhibited the signs and symptoms of someone with mental illness and a personality disorder.

The son did not believe that removing his mother from the ventilator was an option and was unwilling to accept that his mother's comments concerning refusal of tracheostomy were true. He believed he was acting in his mother's best interest by pursuing a tracheostomy, yet further concerns about his capacity were raised based on other exhibited behaviors. He consented to a tracheostomy but denied consent for a PEG tube for feeding without giving a reason. Members of the family expressed inconsistent statements about what the patient would have wanted. An ethics consult was requested to assist with decision making. The son reported that his mother would want "every chance at life" and his wife reported, "She told me she would never want to live in a [nursing] home." Over the next several weeks, Mrs. P continued to be confused, semi-sedated, and restrained, and made little progress on weaning from the vent. During multiple conversations between Tom and the medical staff, he was unable to maintain the "track" of conversation and would become hostile, focus on small unrelated details, and make unreasonable demands (such as knowing the name of all persons who might come in contact with his mother in the next 24 hours, and their role in her care). He demanded to "only speak to hospital administrators" for two weeks, even when the staff explained that the ICU physicians

had more direct and more pertinent information. He visited with his mother twice, for a few days each visit, but would not address her caregivers and spent his time on his phone or laptop. He appeared to most of the staff to be paranoid and hostile.

The ethics committee was notified, three weeks after its initial consult, that the sister-in-law of the patient, Mrs. S, the third agent listed on the POAHC form, and Mrs. S's daughter, the patient's niece, had come to visit from several hours away. The patient's niece was an RN. Both women reported that shortly after the death of Mrs. P's brother, Mrs. P clearly stated that she would not want to be maintained on long-term life support such as a ventilator. Ms S was very upset that Tom was not following the known and expressed wishes of Mrs. P or the wishes that were listed in her POAHC form. Ethics advised Mrs. S and her daughter that they could independently pursue legal action to become the patient's guardian or to remove the current acting POAHC agent via court order, if they believed that the son's actions were not in keeping with the stated wishes of the patient.

Seven weeks into her hospitalization, Mrs. P was not alert and remained restrained on the ventilator, not showing much improvement other than occasionally opening her eyes and crying. After two months, Mrs. P became more alert, but was still confused. She was able to progress to a speaking trach during the day, but required a ventilator at night. During this time, multiple attempts were made to reach Tom for permission to transfer his mother to a LTACH to facilitate greater rehabilitation and final weaning from the ventilator. Tom did not answer or return phone calls. His wife stated that he was "ignoring" her as well. Legal counsel was contacted for an opinion regarding how long to wait for the son's response before the staff could justifiably go to the third POAHC agent for consent. After 72 hours, the son had not replied, and the patient was transferred to LTACH using the consent of the patient's third POAHC agent.

Mrs. P was hospitalized in the ICU for four to six weeks longer than her medical condition warranted. Her extended hospitalization was due to the inability of hospital staff to work in an effective manner with her POAHC agent. Although the team was unable to have the agent's capacity tested, the staff suspected that he suffered from some form of mental illness. This suspicion was also supported by his aunt, the third POAHC agent. In this case, the team would have pursued emergency guardianship had we not been able to utilize the third listed POAHC agent.

COST TO THE HEALTHCARE SYSTEM

Cases such as these present financial risk to an organization, overrun costs for treatments that are neither medically necessary nor advisable, and impede the effective delivery of patient care. Healthcare providers' competence in navigating issues of incapacitated surrogates can potentially minimize costs to an institution. When a patient has a POAHC agent who makes inappropriate decisions regarding the patient's care, oftentimes the hospital staff is unable to expedite a safe discharge plan, and the patient's length of stay (LOS) increases, resulting in complications and hospital-acquired conditions (HACs) for the debilitated patient.⁵ HACs and complications to patients' medical conditions can significantly and unnecessarily increase the cost of medical treatment.⁶ Additionally, financial costs may be significant in pursuit of legal action and guardianship for patients when surrogates' decisions pose a risk of harm to the patients. Legal action, however, is not only costly but takes time, putting patients at risk of HACs and increasing the likelihood that they will require otherwise unnecessary treatment.

If at all possible, an institution would be better served by working with the resources at hand to reach a reasonable solution in the plan of care for such patients. For example in the case of Mr. M, the healthcare team had no medical or legal authority to determine if the POAHC agent *understood* Mr. M's needs, but the agent was consistently willing to work with the hospital towards his brother's benefit. He was willing to learn and take on a caregiving role for his brother at home, and while his comments and viewpoint were at times troubling, his overall concern for his brother appeared to be intact. Rather than incurring large financial costs to remove the agent, the team utilized an interdisciplinary approach to work with the patient's brother to create a compromise on a plan of care.

Psychological impact can also be a significant cost that is carried by the staff. The moral distress caused by the controversial and complex nature of such situations cannot go unmentioned. It is an added concern for maintaining the resiliency of the staff and high-quality services. Moral distress occurs when a person's actions are in direct conflict with what she or he feels should be done for a patient. Staff's feelings that their actions are not in line with the patient's best interests or wishes can lead to moral distress and burnout. The case of Mrs. P, in which her POAHC agent went against her wishes as stated in her advanced directive and what she had told nursing staff, is an example of the moral dis-

stress that can be experienced by ICU nursing staff. The staff expressed feelings of helplessness, anxiety, and anger in managing the care of Mrs. P and in interacting with her challenging surrogate decision maker. Although it may appear, given the patient's statements prior to intubation, that the hospital had no reason to interact with Mrs. P's son as an agent when he appeared to be going against the patient's wishes, that is only correct in theory. In actual hospital practice, staff are often forced to attempt to work with family members who dispute the staff's record of the patient's expressed wishes, deny a patient's prior expressed desires, or claim absolute decision-making authority for the patient, given the POAHC endorsement. The staff, in the case of Mr. M, expressed feelings of moral distress due to a plan of care that might have caused great harm to him.

While the long-term consequences to staff in either case aren't yet known, it can be reasoned that such distress had a negative impact on the quality of patient care. Qualitative research by Gutierrez found that end-of-life care decisions and issues of futility were the biggest sources of moral distress for nurses in a critical care environment.⁷ Gutierrez reported that the psychological effects of moral distress on nurses included feelings of sadness, anger, frustration, guilt, fear, and disgust. Nurses also reported physical symptoms from moral distress such as nausea, vomiting, and insomnia, which in turn could lead to calling in sick and lost work days. Many staff reported the social impact that moral distress had on their family life, expressed as withdrawal from family members or friends. Professional consequences included a reluctance to come to work, a desire to avoid patients and avoid providing primary care, and questioning of their ability to remain in their job. Similarly, Elpern and colleagues reported that moral distress had a direct impact on staff's job satisfaction, psychological and physical well-being, self-image, and spirituality.⁸ These effects, in turn, resulted in a greater incidence of nurse turnover. Without a standard framework for working through complicated situations caused by incapacitated surrogates, healthcare teams are likely to waste valuable time, energy, and resources grappling with such issues.

THE LEGAL ISSUES

When the decision-making capacity of a POAHC agent is in question, legal options for the healthcare system are limited. Statutory safeguards are provided to protect patients with substitution or removal of agents, but virtually all states in the United States

lack a mechanism to specifically address an agent who exhibits questionable decision-making capacity. In the state in which these patients presented, the circumstances of an agent with questionable decision-making capacity are not specifically addressed in the statutory chapter that addresses POAHC.⁹ Even the federal U.S. Uniform Health-Care Decision Act does not include a provision to evaluate surrogates for their lack of decision-making capacity.¹⁰

Patients can elect to designate an alternate agent in their POAHC. If a POAHC provides for an alternate in the event that the primary agent is unable or unwilling, a healthcare provider can turn to the secondary agent as the legal decision maker.¹¹ But this substitution requires that the first agent to *voluntarily* express an inability or unwillingness to serve. Secondary agents also become available when reasonable attempts by healthcare providers to contact the primary agent are unsuccessful. Yet it is often difficult to obtain a voluntary expression of inability or unwillingness to serve from primary agents because they may lack the recognition that they are unable to properly continue to serve as an agent. Without such self-recognition, which may be caused by a variety of reasons, most primary agents do not voluntarily resign. In instances when agents voluntarily resign, documentation is easily performed. But when agents must be involuntary removed, that process can delay necessary decision making, compromise patient care, and increase the length of stay as well as healthcare costs. This is demonstrated in the case of Mrs. P, in which her hospital stay was four to six weeks longer than her condition indicated.

Another statutory safeguard allows patients to revoke their POAHC and invalidate it at any time. This is achieved through several methods.¹² Each requires action by patients and a willingness to remove an agent. None of the presently available safeguards protect patients from an incapacitated surrogate. An alternate safeguard, provided by statute, requires court involvement. This safeguard allows any interested party to petition the court to review whether healthcare agents are performing their duties in accordance with the terms of the POAHC.¹³ In the case of Mrs. P, the third agent was informed of the option to petition the court to remove the first agent, but declined to do so. The third agent stated concerns about the potential costs and length of the process in petitioning the court.

Petitioning the court is a safeguard provided under state statute, but statutes do not allow a healthcare provider to compel POAHC agents to accept an evaluation of their decision-making capacity. This

inability presents a difficulty in presenting the court with evidence that a POAHC agent is unfit or unable to serve as a surrogate decision maker. If a healthcare provider is able to provide direct testimony of a formal evaluation of a POAHC agent's lack of decision-making capacity, the court would be well grounded in the removal of the agent. But a healthcare provider has no authority to subject a POAHC agent to formal evaluation.

An interested party must demonstrate to the court that the POAHC agent is failing to perform his or her duties in accordance with the POAHC instrument, or, alternatively, that the decisions made by the POAHC agent are not in the best interests of the patient. It is a high burden for a healthcare provider to demonstrate to a court that an agent that the patient chose as a surrogate should be removed. Courts are averse to negating patients' decisions regarding their choice of surrogate, and courts are often unwilling to do so unless presented with overwhelming evidence that agents have not acted in patients' best interests. In addition, by the time the matter is presented to a court, decisions concerning the patients often have since long passed and have become moot. In the case of Mr. M, the surrogate had not yet had an opportunity to demonstrate his inability to care for Mr. M properly. The staff's concern was that, when given the opportunity, the agent would not care for the patient properly. There was not yet adequate evidence that the POAHC agent should be removed.¹⁴

THE ETHICAL ISSUES

When valid POAHC forms exist, there is an expectation that the surrogates will follow the explicit directions given by the patients, if any were listed or verbalized, and that the surrogates will have knowledge of the patients' values that can direct care when no explicit directions were given. This way of making decisions is called *substituted judgment*, and it is generally considered the ideal when making decisions for others. The next best approach is to utilize knowledge of the patients' values to determine what is in their best interests, called the *best interest standard*. A third approach used to make decisions for others is called the *reasonable person standard*, and, as the name implies, it relies upon a determination of what reasonable persons would want in similar situations when the particular values or goals of the person are not known. Each of these standards uses the evidence available to make choices for patients when they are unable to express their judgments for themselves. However, none of

these methods directly addresses how staff should respond when there are genuine questions as to the decision-making ability of the POAHC agents to *carry out their duties* under the POAHC forms.

There are very few ways to challenge the decision-making capacities of surrogates. The options seem to be reduced to simple persuasion or costly, slow, legal action. When the capacities of POAHC agents to make appropriate decisions is in question, hospitals may do well to use a two-pronged method to evaluate their capacity, developed by Rhodes and Holzman, the "Not Unreasonable Standard for Assessment of Surrogates and Surrogate Decisions."¹⁵ The not unreasonable standard looks closely at the reasons given for decisions and the outcomes that are expected from those decisions. It also unapologetically requires that a higher bar be used to judge these reasons when surrogates are making decisions for patients. This method of analyzing decision making, first described in 2004, has received little acknowledgment in the literature, and so has been little examined, tested, or verified in practice—or shared with the ethics community for discussion. We seek to reopen this conversation and demonstrate how this two-pronged framework has been helpful in determining when a hospital system is justified in pursuing legal action to remove a POAHC agent.

Generally it is the physician directing a case who first evaluates that a patient has questionable ability or clearly is lacking the ability to make independent healthcare decisions. Society has entrusted physicians to make these decisions and also at times to override a patient's refusal of treatment, if the physician believes the patient is lacking in capacity and the need for treatment is emergent and lifesaving. If the treatment is not emergent or lifesaving, then a psychiatric consult is routinely requested to evaluate a patient's capacity, and if capacity is determined to be lacking, the patient's POAHC form is activated. Once a POAHC form is activated, the POAHC agent has the legal authority that the patient would have had to consent to or deny treatment, transfer, or procedures. However, when the POAHC agent's capacity is questionable or the agent is clearly unable to make informed decisions, physicians and the healthcare system have no power (other than attempts to persuade the agent to voluntarily step down) to mandate a similar evaluation of capacity. Hospital ethics committees are often consulted in an attempt to work with an agent who demonstrates questionable capacity, but committee members are also limited to using their persuasive powers or directing others (if others exist) to begin a legal battle to change to an alternative POAHC agent

or to recommend obtaining guardianship to allow a competent decision maker to prevail. Only in situations when clear danger or maleficence is apparent from the decisions of a POAHC agent do hospital systems resort to legal channels. As seen in our two cases, such clear-cut maleficence is rarely apparent, even when there is ample concern about a POAHC agent's decision making. We believe that the not unreasonable standard is helpful as a marker for the threshold of when to advance to court. The not unreasonable standard utilizes a two-pronged approach: the first prong looks at the *reasons* given for a decision; the second prong looks at what the *likely outcome* a decision may have on the patient. Both prongs help in deciding when a poor decision by a POAHC agent might meet the threshold that marks when to seek court intervention.

When physicians doubt the decision-making ability of a patient, it is either because the patient cannot make decisions due to severe mental or medical conditions (such as being psychotic, on a ventilator, comatose, or demented) or, although the patient is able to state a decision, the patient is unable to meet the requirements for informed consent in making the decision. It has long been accepted that informed consent requires the following components:

1. The ability to receive information.
2. The ability to understand information, including risks and benefits.
3. The ability to evaluate information using the patient's own values.
4. The ability to make a decision that is in the patient's best interests and to give *reasons* that others can understand regarding the decision.

It is the fourth component, the requirement for reasons that others can understand, that is often most

difficult to evaluate in a patient. The requirement that a patient give reasons does not say we must *agree* with the patient's reasons; the requirement is merely that we can understand those reasons in light of that specific patient's values. When a surrogate decision maker is involved, it is often difficult to evaluate the third component as well; that is, evaluating a situation using the patient's values may not be possible when we may have no knowledge of the patient's values nor whether the surrogate is aware of the patient's values or is utilizing them in making decisions for the patient. It is very difficult, if not impossible, to determine what is in another's "best interests" if we have no knowledge of that person's values. Yet we may be able to evaluate what would be "reasonable" or at least "not unreasonable," using an approach described in the next section.¹⁶ This is the first prong of the two prongs used in the not unreasonable standard to evaluate a surrogate's decision making.

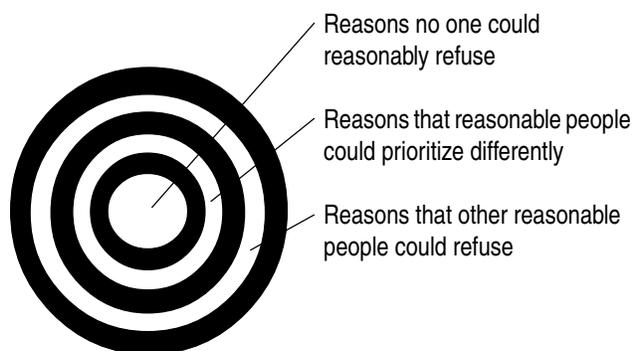
THE FIRST PRONG: THERE ARE REASONABLE REASONS

A broad evaluation of the kinds of reasons used by surrogates is consistent with the levels of reasoning that have long been promoted by James Drane.¹⁷ Drane used three levels, based on how dangerous a refusal of treatment might be to a patient. In developing the not unreasonable standard to evaluate reasons, Rhodes and Holzman also used the work of T.M. Scanlon.¹⁸ Figure 1 depicts a model of the three levels. At the center or core level, there are reasons that everyone would accept (or could not reasonably reject). Such examples might be cleaning out a wound and stitching it up to stop severe bleeding following an accident, or accepting surgery for a ruptured appendix to preserve life. In the same way, refusing stitches to repair a lacerated artery or refusing antibiotics to treat a severe infection would call reasonable persons to question a person's ability to accurately make decisions that are in her or his own best interests.

In the second or middle level are those treatments that may be assessed differently based on individuals' values or risk aversion that lead to refusing a treatment. This could include treatment like chemotherapy when the costs or burdens associated are high and the outcome is uncertain. Reasonable people could understandably prioritize differently when looking at the benefits and burdens of treatment.

The outside rings represent the kinds of reasons that seem very idiosyncratic, but the reasons are

FIGURE 1. Kinds of reasons.



accompanied by logical explanation, and others will be able understand the values that support the reasons. These may include personal commitments, values, or religious views. An example of such a reason that is held by many would be Jehovah's Witnesses who refuse blood transfusion, even when refusal will lead to certain death. Or a reason may be one that is strongly held by only one person; for example, a person who, as a child, lost a parent following surgery and has stated over the course of a lifetime, to all who will listen, that she or he would rather die than go under the knife. A strong value may inform a patient's decision to refuse a treatment or procedure; if that value can be reasonably understood, it is not necessary to agree with it. One patient's strong value may be rejected by other reasonable people, perhaps easily; for example, those who are not Jehovah's Witnesses probably would not refuse blood in a life-threatening situation.

How would the not unreasonable standard work in practice? In the case of Mr. M, his brother, Mr. D, would seem to fail as a surrogate using the best interest standard, because Mr. D did not meet all the requirements of informed consent, namely:

1. The ability to receive information: Mr. D would pass this requirement, as he was involved and concerned.
2. The ability to understand information, including risks and benefits: Mr. D appears to fail this requirement, in that he does not accept that allowing Mr. M to eat a cheeseburger after failing a swallow study could cause aspiration or choking. This lack of understanding is of concern because it could easily endanger the patient.
3. The ability to evaluate information using the patient's own values: Mr. D and Mr. M probably share similar values, as they have lived together for years.

4. The ability to make a decision that is in the patient's best interests and to give reasons that others can understand regarding the decision: Mr. D's failure of the second step of this list may indicate that he cannot pass this requirement.

Utilizing the not unreasonable standard, Mr. D's reasons—"he will do better at home" and "he likes to sleep on the floor," coupled with the staff's belief that Mr. D does know his brother's values—can be evaluated differently than they would be using the best interest standard. Using the not unreasonable standard, Mr. D's reasons are ones that *reasonable people could understand, even if they prioritized differently*. Thus, Mr. D would pass the first prong of the not unreasonable standard.

THE SECOND PRONG: THE LIKELY OUTCOME OF A SURROGATE'S DECISION

The not unreasonable standard does not allow stopping evaluation of a surrogate at the point of understanding the surrogate's reasoning. The second prong requires evaluating how the treatment decisions, based on the surrogate's reasons, will likely affect the *outcomes* for the patient. Outcomes may be seen broadly as fitting into one of three boxes, as depicted in figure 2.

Beneficial outcomes go in Box 1: outcomes that are expected to be good with treatment, and, when treatment is refused, there is an expectation of significant harm. Usually, no reasonable person would refuse the treatment, but an autonomous patient has the right to do so. An example is accepting a blood transfusion for a hemorrhaging injury; a Jehovah's Witness patient may knowingly accept death rather than accept a simple medical procedure, based upon his or her personal values.

FIGURE 2. Outcomes of the second prong of the not unreasonable standard.



- Box 1: Treatment is beneficial
- Required
 - Unreasonable to refuse



- Box 2: Treatment is optional
- More than one reasonable choice
 - Not unreasonable to refuse



- Box 3: Treatment has no significant benefit
- Palliation is preferable

In the middle box, Box 2, the treatments offered and their benefits are less certain, or there are significant burdens attached to the “hoped for” benefits, such as a new line chemotherapy for a lung cancer with metastasis that has not responded to two previous treatments. A surrogate’s choices in these situations may not be characterized as completely unreasonable or irrational because the outcomes are uncertain or highly variable. If we don’t know that the surrogate’s choice will produce a poor outcome, pursuing the court removal of a POAHC agent or pursuing guardianship cannot be justified.

The last box on the right, Box 3, is for outcomes that we expect to be poor regardless of treatment, for example when a patient has a diagnosis of brain death or an invasive, nonresectable tumor that is resistant to chemotherapy. In these cases, treatment may merely prolong dying, and palliative or hospice care would usually be encouraged by a physician. In these cases, even if a surrogate appears to be making a poor decision, it will not affect the outcome *significantly enough* to justify a lengthy and expensive court intervention.

The not unreasonable standard requires a higher standard when a surrogate is making decisions for another person. This is appropriate, given the vulnerability of incapacitated patients and the importance of treatment decisions. A surrogate’s choices can harm the patient, and this is the threshold for legal intervention.

One distinction to be made between deciding for oneself and deciding for an incapacitated other is the difference in reasons. In figure 2, Box 1 collects required, beneficial treatments that would typically be seen as unreasonable to refuse. At the far right of figure 2, Box 3 is for treatments that offer no significant benefit. A decision to refuse a beneficial treatment, at one extreme, and to insist on treatment with no significant benefit, at the other extreme, would be paradigmatically unreasonable, absent some very personal and unusual considerations. Such decisions can only be justified by reasons from the outer domain of the idiosyncratic, or group reasons that other reasonable people can refuse to endorse. Although personal reasons are sufficient to guide one’s own life, because physicians have a fiduciary responsibility to their patients, physicians cannot accept a surrogate’s personal reasons for refusing significantly beneficial treatment when that choice would violate universal values. Unless physicians have strong evidence for believing that the surrogate’s unusual reasons were shared by the patient, they must refuse to honor a surrogate’s refusal of treatment in these situations.¹⁹

The first prong of the not unreasonable standard is a tool to help those working on ethics committees and in healthcare to begin deeper discussions with POAHC agents regarding the agents’ core reasoning as they make decisions for patients. The second prong of the standard helps members of ethics committees and healthcare providers to directly tie agents’ decisions to the outcomes for patients. If POAHC agents are unable to give a reasonable justification when they make a decision to refuse a treatment with a likely good outcome, a case can be made to pursue legal channels. The not unreasonable standard is a solid and reasoned process to evaluate surrogates when the hospital questions their capacity to make decisions for their patients. When POAHC agents are not able to meet the not unreasonable standard, it may be necessary to pursue legal channels to protect vulnerable patients.

It is not easy to remove patient-appointed POAHC agents, and it is unlikely to become easier in the future. Thus it is important to evaluate those agents whose decision making we question, to determine which cases should be pushed to legal limits. But it is important to balance concerns for patients’ well-being or beneficence against the harms of overriding their prior autonomy in selecting a POAHC agent. All hospitals suffer limited resources, and we do not want to overburden the legal system, but we must protect the best interests of patients who may not be served by their surrogates. Although the not unreasonable standard requires us to prod surrogates’ reasoning more deeply, it may sometimes allow us to prevent costly court battles when it appears that surrogates may not be capable. The efforts required to question surrogates’ reasonings and have them made explicit are justified by concerns for the well-being of patients.

Going back to the case of Mr. M: while his surrogate’s judgments may have seemed questionable, the patient’s outcome may not have been dramatically different whether he returned home or went to a skilled nursing center. This, and the likelihood that the brothers shared numerous values because they had lived together for many years, makes it easier to accept the decisions of the surrogate, even though they were not what had been recommended by the medical professionals. Concepts of “the good” are individually constructed and include both health and nonhealth issues, such as wanting to support Mr. M’s values related to being at home and eating his favorite foods. There was a possibility that Mr. M’s brother was benevolently maleficent, by engaging in a harmful action while having a disposition to do good for patient. But he did not refuse a feed-

ing tube for the patient, and did agree to learn what was needed to allow him to take his brother home, showing that he was not unreasonable and was willing to compromise. Although the surrogate's plan was perhaps not what the hospital staff thought was optimal, it was a plan that was ultimately consistent with the patient's values, and not completely unreasonable.

In the case of Mrs. P, it was clear that her son was not using substituted judgement because he did not follow what was written in Mrs. P's advance directive regarding her wishes for not being maintained on life support. The son also denied having had any specific conversations with his mother on the topic of being on a ventilator, and refused to believe a documented conversation in which Mrs. P stated that she would not want a tracheostomy. Using the not unreasonable standard, here is an examination of the capacity of the son/agent to discern the patient's best interest:

1. The ability to receive information: The patient's son was not always willing to participate in information sharing and would not accept recommendations or prognoses as valid.
2. The ability to understand information, including risks and benefits: It was often difficult or impossible to evaluate the son's understanding due to his not being readily available or willing to communicate, and his tendency to force conversation to irrelevant subjects such as who the insurance reviewers were and how to contact them.
3. The ability to evaluate information using the patient's own values: The son failed to acknowledge the patient's values as recorded in her advance directive. The son held that the patient "would want everything done."
4. The ability to make a decision that is in the patient's best interests and to give *reasons* that others can understand regarding the decision: Although it was unexpected, Mrs. P did end up improving, at least upon hospital discharge, to the point of sitting in a chair, being alert, and being able to communicate (even if the communication was confused). Mrs. P still required a ventilator at night, and it is possible to question whether her values and interests supported a greater quality of life versus the quantity of days in her life, as her son maintained.

Using the not unreasonable standard to evaluate the capacity of the son's decision making as a surrogate, it is possible to determine that his decision to proceed with tracheostomy and ongoing ventilator sup-

port was a decision that reasonable people could prioritize differently, and its outcome could be variable or uncertain.²⁰ Thus, progressing in ongoing medical treatment in accordance with the decision of the POAHC agent (even though this was not what Mrs. P had stated as her wishes) can be seen as an acceptable option and in keeping with supporting life. But the son's decision to refuse to return calls requesting authorization to transfer the patient to the next level of rehabilitation care was a decision that most persons would say no one would reasonably refuse (that is, moving to the next step in healing). A decision to move the patient to a lower care level had a high likelihood of a good outcome and benefits to the patient, as it would allow weaning her off mechanical ventilation and increasing her strength and independence. Not moving the patient from the ICU posed risks of significant harms such as nosocomial infections and setbacks. At that point, removing the son as surrogate and approaching an alternative agent named in the POAHC was justified. Using the not unreasonable standard, if the patient had not named alternative agents in the POAHC, the threshold to involve legal channels would have been reached.

In this case, the staff was left greatly dissatisfied with the outcome. Using the not unreasonable standard addresses the *capacity* of a surrogate and not the pure *content* of a surrogate's decision making (that is, in this case the son did not follow the patient's wishes). Still, use of the not unreasonable standard in this case would lead to removing the surrogate via legal channels, due to the real harms to the patient posed by the surrogate's treatment decisions. Further work and greater moral courage will be needed to access legal channels when competent surrogates choose to ignore patient's wishes documented in advance directives.

CONCLUSION

As increasing numbers of people suffer from debilitating illness, substance abuse, and cognitive deficit due to dementia-type illness or mental health disorders, healthcare systems may be called upon to navigate the complexities of patient care with an increasing likelihood of potentially incapacitated POAHC surrogate decision makers. The current inability to address incapacitated agents in a timely and efficient manner can result in significant unnecessary (and often uncompensated) costs to the institution and to patient care. The not unreasonable standard offers a framework from which to navigate these complex cases. Technological advances

increase the complexity of evaluating the benefits and burdens of treatment; they also make decision making about potential treatments and procedures more complex. Holding a POAHC agent to a higher standard of decision-making capacity is acceptable, given concerns for vulnerable patients. Healthcare institutions can utilize the two-pronged method in the not unreasonable standard to evaluate the decision making of POAHC agents to assist in determining when to pursue time-consuming and expensive legal channels to ensure that patients receive proper, effective, timely, and high-quality care.

PRIVACY

Although the cases described in this article are real, the characteristics and names of all of those described have been changed to assure anonymity and continued confidentiality for those involved.

NOTES

1. D.I. Shalowitz, E. Garrett-Mayer, and D. Wendler, "The accuracy of surrogate decision makers: A systematic review," *Archives of Internal Medicine* 166 (2006): 493-97.

2. K. Baerøe, "Patient Autonomy, Assessment of Competence and Surrogate Decision-Making: A Call For Reasonableness in Deciding For Others," *Bioethics* 24, no. 2 (2010): 87-95. doi:10.1111/j.1467-8519.2008.00672.x.

3. K.A. Bramstedt, "Questioning the Decision-Making Capacity of Surrogates," *Internal Medicine Journal* 33, no. 5-6 (2003): 257-9.

4. In the state of Wisconsin, unless stated otherwise in the POAHC instrument, an advance directive that names an individual as power of attorney must be activated by either two physicians or a physician and a psychologist who have a finding of incapacity regarding a patient, in order for the agent to have authority to be a legal decision maker.

5. K.M. Gutierrez, "Critical Care Nurses' Perceptions of and Responses to Moral Distress," *Dimensions of Critical Care Nursing* 24, no. 5 (2005): 229-41.

6. E.H. Elpern, B. Covert, and R. Kleinpell, "Moral Distress of Staff Nurses in a Medical Intensive Care Unit," *American Journal of Critical Care* 14, no. 6 (November 2005): 523-30.

7. Gutierrez, "Critical Care Nurses' Perceptions," see note 5 above.

8. Elpern, Covert, and Kleinpell, "Moral Distress of Staff Nurses," see note 6 above.

9. Both patients in the cases presented resided in the state of Wisconsin. As a result, the legal issues related to their POAHC instruments are discussed in the context of Chapter 155, which is the governing chapter for POAHC instruments in the state of Wisconsin.

10. See Uniform Health Care Decisions Act §§ 1-19, 9 U.L.A. 93 (1993).

11. Wis. Stat. 155.05 (5).

12. Wis. Stat. 155.40 provides the following methods to revoke a power of attorney. The patient (1) cancels, defaces, obliterated, burns, tears, or otherwise destroys the power of attorney for healthcare instrument or directs another in the presence of the patient to so destroy the power of attorney for healthcare instrument; (2) executes a statement, in writing, that is signed and dated by the patient, expressing the patient's intent to revoke the power of attorney for healthcare; (3) verbally expresses the patient's intent to revoke the power of attorney for healthcare, in the presence of two witnesses; (4) executes a subsequent power of attorney for healthcare instrument.

Many states allow for revocation of a document and removal of an agent, irrespective of whether the document is activated.

13. Wis. Stat. 155.30 (4) (a).

14. Alternatively, in those circumstances when it would not be prudent to proceed with court involvement, but a patient's physician still does not agree with the agent's decisions or ability to serve as a proper agent, in order to preserve the immunities under the statute, the physician must make a good faith attempt to transfer the patient to another physician who will comply with the decisions of the agent. The likelihood of another physician accepting would be low, but, with sufficient documentation of the good faith attempts, the action preserves the immunity provided under the statute.

15. R. Rhodes and I. Holzman, "The Not Unreasonable Standard for Assessment of Surrogates and Surrogate Decisions," *Theoretical Medicine and Bioethics* 25, no. 4 (2004): 367-86.

16. *Ibid.*, 132.

17. J.F. Drane, "Competency to Give an Informed Consent," *Journal of the American Medical Association* 252, no. 7 (1984): 925. doi:10.1001/jama.1984.03350070043021.

18. T.M. Scanlon, *What We Owe Each Other* (Cambridge, Mass.: Belknap, 1998).

19. Rhodes and Holzman, "The Not Unreasonable Standard for Assessment of Surrogates," see note 15 above.

20. It is important to note that we do not address in this article the important, yet separate, issue that Mrs. P's son did not follow her advance directive on issues regarding ventilator care. He was adamant that he was the legal agent authorized to make all decisions. This is a situation that is all too common in many hospitals.