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# Surrogate Medical Decision Making on Behalf of a Never-Competent, Profoundly Intellectually Disabled Patient Who Is Acutely Ill

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## ABSTRACT

With the improvements in medical care and resultant increase in life expectancy of the intellectually disabled, it will become more common for healthcare providers to be confronted by ethical dilemmas in the care of this patient population. Many of the dilemmas will focus on what is in the best interest of patients who have never been able to express their wishes with regard to medical and end-of-life care and who should be empowered to exercise surrogate medical decision-making authority on their behalf. A case is presented that exemplifies the ethical and legal tensions surrounding surrogate medical decision making for acutely ill, never-competent, profoundly intellectually disabled patients.

## INTRODUCTION

Intellectual disability, defined as significant limitation in cognitive functioning and adap-

tive behavior covering everyday social and practical skills originating prior to age 18,<sup>1</sup> affects approximately 3.1 percent of the general population in the United States<sup>2</sup> and 120 million individuals worldwide.<sup>3</sup> With improvements in medical care and resultant increasing longevity, this population is expected to grow in size.<sup>4</sup> It is easy to foresee that healthcare providers and medical ethicists will be confronted by dilemmas surrounding what is in the best interest of patients who have never been able to express their wishes with regard to medical and end-of-life care and who should be empowered to exercise surrogate medical decision-making authority on their behalf. A case is presented that exemplifies the ethical and legal tensions that surround surrogate medical decision making for never-competent, profoundly intellectually disabled patients who are acutely ill.

## CASE PRESENTATION

Mr. M, a 45-year-old African-American male with profound intellectual disability (IQ<25 using standardized testing), presented to the emergency department of a tertiary care hospital with a chief complaint of respiratory distress and subsequent cardiac arrest. Mr. M was a resident at a facility that is certified by the Intermediate Care Facilities for

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People with Mental Retardation Program of the U.S. Department of Health and Human Services. The etiology of Mr. M's intellectual disability was unknown, but the degree of his impairment had left him, from childhood, unable to communicate beyond facial expressions of pain and completely dependent on staff support for all activities of daily living. Mr. M carried an additional diagnosis of a seizure disorder and had previously undergone tracheostomy and gastrostomy tube placement for assistance with respiration and feeding. The hospital to which Mr. M was transferred, after emergency medical services resuscitation at the facility, has a contract to provide outpatient and inpatient care for residents of the intermediate care facility and has approximately 300 inpatient admissions by residents from the facility annually.

Per staff from the intermediate care facility and emergency medical services, Mr. M was in his usual state of health when he suddenly became cyanotic with respiratory distress and subsequently pulseless. Standard cardiopulmonary resuscitation was initiated with ventilation provided via the tracheostomy tube and resultant return of spontaneous circulation. On arrival to the emergency department, Mr. M was hypotensive and had a profoundly low oxygen saturation of 79 percent. He was given intravenous fluids and supplemental oxygen with resultant improvement in his vital signs. At this point, he was admitted to the intensive care unit for a presumed respiratory arrest of unclear etiology.

Due to a high inpatient census, Mr. M remained in the emergency department for the next 12 hours. During that time, he became more unstable and was noted to have abdominal distention. A computed tomography (CT) scan of the chest, abdomen, and pelvis was ordered, which revealed that Mr. M had free air within the abdomen, likely due to perforated bowel. General surgery was consulted and agreed that the only available treatment was operative intervention, although the gravity of the patient's current condition and underlying poor functional status made it very likely that such intervention would be unsuccessful.

Mr. M had been a resident of the intermediate care facility since his early childhood, and his parents had signed paperwork at that time that allowed the facility to consent to emergency treatment without first notifying the family. Mr. M's parents had also obtained court-appointed guardianship for him, but by the time of this emergency department presentation, both parents had died, and the guardianship had not been conveyed to his siblings. A sister was the closest living relative and was the family contact for the institution with regard to Mr. M's ongoing care. In the emergency department, both Mr. M's sister and the administration of the intermediate care facility were contacted regarding the new CT

findings and were told that the only available options were surgical intervention or palliative care. It was made clear to both that Mr. M's condition was grave and that, in all likelihood, he would expire even with operative treatment.

Mr. M's sister expressed to the surgeon, the emergency physician, and the intensive care staff that she would not consent to surgical treatment. She and her siblings had noted that their brother had shown signs of physiological decline and a need for repeated hospitalizations on a more frequent basis in the last few years, and they had hoped to discuss with the intermediate care facility the initiation of do-not-resuscitate status and palliative care prior to this episode. Mr. M's sister said that she preferred that palliative care measures alone should be initiated, and that her brother should not undergo a surgical procedure that had a high likelihood of failure, which would subject him to multiple potential complications.

When the sister's views were conveyed to the intermediate care facility, the administrator for that institution took the position that the sister could not refuse to consent to the surgical option if it provided any hope of saving the patient's life. Citing the fact that Mr. M had never been able to express for himself what he would want under these circumstances, and that his parents had previously allowed transfers for emergency medical care under the discretion of the institution in which he had been resident for nearly 40 years, the administrator of the intermediate care facility took the position that, with the availability of a mode of treatment, even if it was unlikely to succeed, all efforts should be expended to save Mr. M. In addition, the administrator cited statutory and regulatory mandates that were interpreted as requiring the hospital to move forward with treatment if requested by the facility (discussed further below).

Faced with this conflict, an emergent ethics and legal recommendation was requested with regard to the appropriate course of action for Mr. M.

## ANALYSIS

This case presents a number of ethical and legal dilemmas that surround the care of the profoundly intellectually disabled. Unlike patients who previously had intact medical capacity, the profoundly intellectually disabled have never been able to express for themselves what the goals of their medical care should be and when acute interventions should be foregone and palliative care initiated. In approaching this case, the ethics consult subcommittee and le-

gal counsel of the hospital articulated the following interrelated concerns.

### **1. Who Should Have Priority in Making Medical Decisions for This Patient?**

On its face, the contention by the intermediate care facility that it should be able to supersede the decision-making authority of loving, involved family members who have a long-term relationship with the patient, and, by all evidence, have his perceived best interest at heart, seems unreasonable. On reflection, however, there is a credible argument to be made for the intermediate care facility serving as the surrogate decision maker for its residents. For the profoundly intellectually disabled, who are completely dependent upon such facilities for their activities of daily living and who have largely experienced life only in this setting, it can be argued that these institutions are, in essence, surrogate parents. In addition, family members of the profoundly disabled have largely turned over their care to these facilities, as their family members recognize that the resources required to maintain the patients can only be provided in such a setting, almost always with governmental support. Finally, in choosing to place their loved one in the care of such a facility, families at least tacitly acknowledge that there is an inherent interest in preserving the life of the profoundly intellectually disabled, regardless of the perception of the quality of life experienced by the patient, and that the facility will need to represent that interest in emergent circumstances.

In this case, Mr. M's parents had placed him in the care of this intermediate care facility from childhood and had provided for the facility to consent to medical treatment in acute circumstances. The facility argued that the delegation of consent authority meant that it had the ultimate responsibility for serving as the medical decision maker for its residents, even when family members were still involved with patients. Mr. M's parents had not transferred their guardianship to his siblings, which at least raised the possibility that his parents wished to leave the care of Mr. M in the hands of the facility with regards to medical decision making. Finally, the

facility contended that Mr. M's residence over nearly 40 years had created a *de facto* state of guardianship for him, and that its daily care for him meant that it best understood his best interest.

On further reflection, however, to rely on the intermediate care facility when family members were available, involved, and attempting to make decisions on behalf of Mr. M would be untenable unless the family members were not representing his best interest. As a practical matter, his family members had the ability, if they disagreed with the care provided by the intermediate care facility, to remove Mr. M from that location and place him in an alternative facility that agreed with their decisions regarding the best course of action, even with governmental financial support. The intermediate care facility for Mr. M did not contend otherwise and had not previously petitioned a court for guardianship of Mr. M (or any other resident), even when their family members were absent. In addition, from a pragmatic standpoint, if Mr. M were to undergo surgical intervention and there were complications requiring care beyond the capabilities of the intermediate care facility, it would be his family who would have the responsibility to care for him in a different long-term acute-care setting. These two factors, and the traditional presumption that next of kin generally should serve as surrogate decision makers for incapacitated family members, weighed heavily upon both the ethics consult subcommittee and hospital's legal counsel in suggesting that Mr. M's family members should have greater standing than the intermediate care facility in making medical decisions for him, unless some other larger ethical principle outweighed such practical and generally accepted considerations.

### **2. What Are the Ethical Principles That Should Govern Medical Decision Making for This Patient?**

This case differs from the vast majority of instances in which ethics consultation is requested because Mr. M at no point in his life was ever able to express what his wishes would be in these circumstances, even in a tangential

or conversational sense. The fundamental ethical principle of autonomy and its corollary of informed consent therefore could not be applied in the usual manner. Similarly, neither Mr. M's family nor the intermediate care facility, in its attempts to provide substitute decision making on his behalf, could infer what his wishes would be in this circumstance.

As such, the core ethical standard brought to bear in this case was what was in Mr. M's best interest, given the medical facts. In applying a best interest standard analysis to this case, the ethics consult subcommittee was faced with two competing interpretations. From the perspective of the intermediate care facility, the only clear path to follow the best interest of Mr. M was to pursue all medical interventions to preserve life. While the vast majority of the general population have been reported, in survey studies, to prefer the withholding or withdrawing of life-sustaining treatment when faced with an end-stage condition or a state of permanent unconsciousness or dependency, the intermediate care facility rightly noted that, for Mr. M and patients like him, such dependency and life experience were all they had ever known.<sup>5</sup> It also noted that, in the absence of clearly stated wishes by Mr. M regarding his course of treatment, it was dangerous to presume when he would want to prevent the institution of a course of treatment that might preserve his life, even if the likelihood of success was small. Finally, from a larger perspective, the intermediate care facility cited the traditional principle of *parens patriae* (the duty of society to protect those constitutionally unable to support themselves),<sup>6</sup> to put forward the notion that, as the representative of society through its credentialing from and regulation by the U.S. and state governments, it was well within its prerogative to argue that the ultimate best interest of Mr. M would be to preserve his life, unless it was medically certain that all treatments had been exhausted. In essence, the larger burden, from the ethical perspective, was on his family members to explain why palliative care and subsequent death were in his best interest.

For the members of Mr. M's family, the best interest standard required a broader understand-

ing of the life experience of their loved one. Their concern that Mr. M had shown a physical deterioration recently and had required repeated hospitalization away from the environment with which he was most familiar, if not cognizant of, indicated to the ethics consult subcommittee that the family's view of Mr. M's best interest was centered on both his physical health and the suffering he might experience by this intervention. Norman Cantor, in his book *Making Medical Decisions for the Profoundly Mentally Disabled*,<sup>7</sup> characterizes such analysis best when he states that the fundamental issue of human dignity is at the center of what defines personhood and is where the best interest of a profoundly intellectually disabled person must be centered. In Cantor's argument, human dignity includes the right of individuals to refuse bodily invasion that can characterize medical and surgical treatments, particularly when instituted with little likelihood of success. While Mr. M could not himself ever express where that limit might lie, it would potentially be a fundamental violation of human dignity to state that, for all profoundly intellectually disabled patients, unlike other individuals with preserved or previously intact decision-making capacity, there was never a point at which medical interventions could be withheld, short of the very end of life or the complete loss of consciousness.

Where to draw such a line, if one accepts the human dignity construct as governing in this case, is not clear. Is the line crossed only in extreme critical illness, as was the case with Mr. M, or would it potentially extend to other scenarios, such as the institution of dialysis for chronic kidney disease or coronary artery bypass grafting in the setting of a heart attack? If the goal of ethics consultation is to provide clear, cogent, and reproducible application of moral principles to clinical situations, the position advocated by the intermediate care facility was the "brightest line" that could most easily be translated across a number of clinical scenarios. To ignore the particulars of the case, however, in the opinion of the ethics consult subcommittee, was to only look at Mr. M in the abstract and ignore the maxim that "good facts make good ethics."

It should be noted that at no point did the consult subcommittee perceive any secondary consideration was involved in the ethical positions of the two parties. Specifically, financial burdens on the family or financial gain for the intermediate care facility by continuing to maintain Mr. M were not raised by either party.

Ultimately, the consult subcommittee determined that while there was comfort and ease in defaulting to a position of preserving life at all costs, a richer analysis indicated that Mr. M had an interest both in preserving life and dignity with regard to continued medical intervention. While a bright-line articulation would be difficult, the extreme gravity of Mr. M's medical condition and the high likelihood of pain and medical complications, should he survive, in contrast with providing comfort to a patient who in all likelihood was dying, seemed to point to a conclusion that the best interest of Mr. M lay in allowing withholding surgical intervention. At worst, it was felt that both parties had articulated the best interest of Mr. M to a largely equal extent in the balance of preserving life versus dignity.

### **3. What Are the Statutory, Regulatory, and Precedential Factors?**

While the consult subcommittee had come to a consensus on the ethical analysis of this case, it was readily acknowledged that legal mandates may override this analysis and force a different clinical course for Mr. M. In this jurisdiction, two statutes and one state supreme court decision, per the hospital's legal department, were relevant. Act 169 of 2006 in the Commonwealth of Pennsylvania set forth a statutory framework on healthcare decision making in the state.<sup>8</sup> In section 5462(c)(1) of this law, the state mandated that next of kin who are not healthcare powers of attorney may not force an attending physician to withhold or withdraw life-sustaining treatment unless the attending physician agrees that the patient has an end stage medical condition or is permanently unconscious. In a 2010 Pennsylvania State Supreme Court Case, *In Re: D.L.H.*,<sup>9</sup> the majority opinion affirmed that this section applies to family members serving as a surrogate

decision maker for never-competent patients. Finally, section 417(b) of the Pennsylvania Mental Health and Mental Retardation Act of 1966<sup>10</sup> indicates that the director of a facility could direct medical care for residents of the facility, but section 417(c) indicates that elective surgery could only be consented to by a facility in the absence of family.

Legal counsel at the hospital therefore focused on two points. First, what constitutes life-sustaining treatment? Act 169, in a somewhat circular manner, defines "life-sustaining treatment" as those procedures and interventions that serve only to prolong the dying process for a patient who has an end-stage medical condition or who is maintained in a state of permanent unconsciousness. Where that line is drawn has not been established by legal precedent, but is presumed at this hospital and in general medical practice to be those treatments that maintain vital bodily functions by artificial means, such as endotracheal intubation and ventilation, cardiac pacemakers, and artificial feeding tubes, which are specifically mentioned in the act. Under that interpretation, the hospital legal department did not feel that Act 169 compelled surgery for Mr. M, as it would not maintain a vital bodily function *per se*, but rather was one potential course of treatment among many.

Second, did provisions of the Pennsylvania Mental Health and Mental Retardation Act of 1966 automatically place the intermediate care facility ahead of family in medical decision-making authority for its residents? Legal counsel to the hospital felt the act only allowed such priority in the absence of family, based on section 417(c), although, again, no legal precedent in Pennsylvania had clearly resolved the apparent conflict between section 417(b) and (c).

In conclusion, it was felt that there was no legal mandate that would override the ethical analysis of the situation that was provided by the consult subcommittee in this case.

### **OUTCOME OF THE CASE AND FURTHER RECOMMENDATIONS**

Based on the pragmatic issues that pointed to decision-making authority residing with the

family, concerns that surgical intervention would subject Mr. M to undue pain and medical complications without a significant likelihood of success and an apparent lack of legal mandate in this circumstance, the recommendation of the ethics consult subcommittee was that it was appropriate for the emergency department, intensive care, and surgical staff to follow the wishes of Mr. M's sister and forego surgical intervention in favor of palliative care. This was conveyed to the intermediate care facility. The next day, the attorney for the facility contacted hospital counsel contending it would go to court to compel intervention based on its interpretation of Mr. M's circumstances and perceived best interest, along with its regulatory obligations in this regard. By this time, Mr. M had manifested polymicrobial bacteremia and such severe hypotension that he was no longer felt to be a candidate for surgery under any circumstances. When this was conveyed to the intermediate care facility, no court case was pursued and Mr. M died under palliative care shortly after.

As a result of this case, a series of discussions have occurred between the ethics committee, the medical staff, the administration of the hospital and the administration of the intermediate care facility to determine if consensus could be reached as to who should ultimately make medical decisions on behalf of those residents who never had medical capacity nor were ever able to express their wishes regarding medical treatment. To date, no such consensus has been reached, and it is anticipated that, if such a situation should occur again, a test case will be brought to allow judicial clarification in the light of the ethical and legal factors outlined above. Recent guidance from the state agency that regulates facilities for the intellectually disabled suggests that family members be given precedence in medical decision making, when available. However, the same guidance calls for the involvement of the directors of facilities in decisions that may result in the withholding or withdrawing of critical medical treatment.<sup>11</sup>

It must be acknowledged that courts, unfamiliar with the particular circumstances of the

involved patient, may default to a position in which the preservation of life in all circumstances is the simplest standard to establish. This is the easy theoretical conclusion and may result from a lack of familiarity with the practical factors involved in compelled medical treatment.<sup>12</sup> It would therefore be important in such a case for the petitioning family or hospital to explain how certain forced medical treatment, as in this case, can subject a patient to pain and suffering with little chance of recovery.<sup>13</sup> There also is a due process argument that to deny the possibility of refusal of medical treatment in the profoundly intellectually disabled is discriminatory when both competent adults and previously competent adults have such a right, with informed judgment and through advanced directives.<sup>14</sup> Such potential for discrimination is reinforced by evidence that surrogate decision makers may be more likely to consent to escalating critical care interventions for others compared with themselves, revealing the need to prevent a default position of the preservation of life under all circumstances.<sup>15</sup>

A better standard would be the aforementioned consideration of the patient's best interest, which should include the possibility of preserving both the patient's life and dignity. Such a dignity interest would take into account the pain, complications, and burdens that can arise from compelled medical intervention, the likelihood of long-term survival without suffering, and any nonverbal means of communication shown by the patient, such as facial expressions of discomfort or unwillingness to comply with treatment. Such a best interest standard, if established in such a case, would also have the benefit of keeping personal medical decisions in the proper forum of the private doctor-patient relationship and not subjected to recurrent judicial reviews that may be influenced by political pressures.<sup>16</sup> Appeals to judicial intervention may also unfairly provide advantage to agencies and institutions that are familiar with the statutory and regulatory issues involved and have resources to pursue legal action.<sup>17</sup> It would therefore be important for the test case to be brought by a patient's family in concert with a hospital to allow a fair presentation of all the

medical, ethical, and legal issues involved. The hospital's standing in such a procedure would be valid based on the importance of maintaining the integrity of medical practice that might be violated by compelled treatment against a patient's best interest.

### LESSONS LEARNED

#### 1. The Importance of the Particulars of the Case

As noted above, "good facts make good ethics." In essence, while abstract analyses of hypothetical situations can aid in the elucidation of ethical principles, it is the particulars of a situation to which ethical precepts must be applied. In this case, pragmatic analysis of the medical prognosis of the patient, the authority of both involved parties, the legal precedents that governed in this jurisdiction, as well as application of fundamental ethical principles contributed to the recommendation provided by the ethics consult subcommittee and hospital legal counsel. Failing to consider these specifics raises the possibility that ethics consultation will be viewed as only providing a theoretical, rather than practical, benefit to all parties involved.

#### 2. The Ethical Challenge of Improving Longevity in Previously Short-Lived Patient Populations

It does seem clear that with improved longevity in patient populations such as the intellectually disabled, new ethical considerations will have to be brought to bear. Previously the focus of ethical dilemmas for the intellectually disabled lay in their treatment during shortened life expectancy or issues of reproduction. Ethics committees will increasingly have to address cases for this population that involve the interaction of factors such as ageing, intellectual disability, and possibly the absence of family. This also represents a larger societal issue. What are the limits of medical decision-making authority for family, institutional, or court-appointed guardians of individuals who never could express their wishes regarding medical and end-of-life care as they face the diseases of age? There is a simplicity in defaulting to a position of pre-

serving life at all cost; but to never acknowledge that palliative care is appropriate is to accept that potential legal liability trumps moral and ethical mandates to preserve human dignity.<sup>18</sup>

#### 3. "Emergent" Ethics Consultation

A final consideration in this case is that, unlike many ethics consultations, there was a critical window of time in which a recommendation needed to be made. As a practical matter, delay in surgical treatment for any significant time would have been equivalent to initiating futile treatment, given the critical nature of the patient's illness. This raises the issue of whether it is valid to expect that the analytic methods required for in-depth ethics consultation can be well applied in such a shortened period of time. This case seemingly required a relatively quick recommendation and resolution, and, fortunately, this center, as with others, had a mechanism in place to allow immediate ethical guidance through an on-call ethics consult subcommittee. One lesson from this case is that ethics committees should consider the development of a mechanism for quick recommendation when appropriate or risk being deemed irrelevant in the most exigent circumstances.

### MASKING OF THE CASE

Details in the narrative of Mr. M in this case that might identify any person involved have been either removed or altered so that the substance of the issues raised may be presented without infringing privacy and/or confidentiality.

### NOTES

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18. Cantor, see note 5 above; Cantor, see note 7 above; Spike and Greenlaw, see note 15 above.