Courts and Controlled Chaos:
An Interpretation of medical Decision Making for Incompetent Patients through Art

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If a competent patient seeks health care treatment, the court has established strict standards that protect the patient's right to determine his or her own care. Stemming from John Stuart Mill's famous declaration "Over himself, over his own body and mind, the individual is sovereign," competent patients have the legal right to accept and deny even life-saving treatment.[1] Since this rise of autonomy between 1960-1990 has been upheld in courts, the decision-making process in cases with competent patients is linear—albeit family members or physicians may disagree with the decision—and ensures that patients' wishes are respected.

In many other cases, however, individuals are incompetent to make decisions for themselves, which begs the question: Who decides? There are many categories of incompetent patients in medical cases, including children, mentally ill, unconscious, and profoundly mentally compromised. Family members and physicians compete for power in such decisions to attempt to prove that they know the best interest of the patient. As explained in Responsibility for Decisions, "the image of isolated patient interacting with isolated physician is a myth."[2] Instead, decision making revolves around perspectives of patients, physicians, family members, and even the hospital, professional boards, insurance and society. This chapter continues with an example of the question of continuing care for a dying newborn infant with trisomy-18. The father did not want to save the child unless it could be "normal," which created questions about the concept of normalcy and the mental state of the father, while the nurse in charge of the baby believed that the life should be saved at all costs; meanwhile, the chief of pediatrics and social worker have their own opinions about others' decisions. The chapter argues that one perspective cannot tell the entire story, but viewpoints must interact to illustrate facts and ethical values at stake.[3] With such diverging opinions, however, how can the best interest of the patient be recognized?

It was in reflecting on these often antagonistic and multifaceted perspectives that I entered the Museum of Fine Arts Boston to explore art through the lens of medical decision making and quickly noticed *Splendid* by Shinique Smith, a modern piece that consists of a large opaque turquoise wood panel with a large mess of tangled webs of intersecting paints and strings. Each layer of acrylic paint, ink shapes, and braided yarn overlaps to create texture in this work, some combining together yet each noticeably distinct. Most protruded from the wood are eight pieces of scrunched fabric randomly assorted throughout the piece, attempting to conjoin into some sort of harmony or clarity. I resonated with *Splendid* because of its concise connection to health care decision-making—the confusion and tension of these decisions mirrored in the piece's overwhelming colors and medium. With so many pieces of scrunched fabric, there is no focal center to the piece, no consensus of the correct interpretation or health care decision. Just as patients' wishes are somewhere within others' perspectives, the first layer of the work remains intact, yet it is hidden by other diverging subsequent layers and can never be fully retrieved. My interpretation of abstract art reveals my own identity in relation to the work in the same way that perspectives of the best interest for patients are skewed by relationships and identities of each individual in the discussion. In the end, all we see is a tangled mess.

One landmark case that represents the complexity of medical decision-making for the incompetent is the case of Karen Ann Quinlan, a twenty-one-year-old woman who went into a comatose state after drinking alcohol and ingesting Valium at a party and ended up in a persistent vegetative state. After three and a half months of no recovery, the Quinlan family decided that "Karen would never want to be kept alive on machines like this" and signed a letter authorizing their discontinuance of a ventilator.[4] Despite initial approval, Dr. Morse told them the next morning that he morally refused to follow the family's request, which plunged the Quinlan family into a battle to gain approval to remove the ventilator and allow Karen Ann to die.

The Quinlan case, in addition to being a case of first impression, contained moral and religious elements that complicated decision-making. Catholic groups protested the Quinlan family's distinction between ordinary and extraordinary means to sustain life, despite their bishop's approval.[5] The case also evaluated the distinction between killing a patient and letting a patient die that was later reestablished by the 1980 Vatican Declaration on Euthanasia: "One cannot impose on anyone the obligation to have recourse to a technique which is already in use but which carries a risk or is burdensome. Such a refusal is not the equivalent of suicide; on the contrary, it should be considered as an acceptance of the human condition."[6] Confusion about opinions, moral standards, and the best-interest of Quinlan led to an intense dispute before the final decision to allow removal of the ventilator.

While comparing health care decisions for the incompetent such as Quinlan to *Splendid*, it is easy to espouse an only negative view of the complexity of health care decisions—these intricacies create tension and extend the decision-making process. As I continued through the Museum of Fine Arts, however, I kept returning to an impressionist piece entitled *Rehearsal of the Pasdeloup Orchestra at the Cirque d'Hiver*. In this painting, an orchestra rehearsal is illustrated sectioned into instruments; cellos, violins, trumpets, and a large drum sit separated in the amphitheater. At first glance, *Rehearsal of the Pasdeloup Orchestra at the Cirque d'Hiver* echoes *Splendid*'s twirling chaos with noticeably impressionist, large, swirling brushstrokes from the upper left-hand corner of the piece, but the painting remains centered by a conductor on the left hand edge of the frame. All sections face the conductor, playing their instruments in the midst of an arrangement.

The idea of an orchestra, blending sounds from different instruments to create beautiful musical compositions, in its rehearsal phase captured for me the power of controlled chaos. Each instrument adds chords and progressions to the piece—impossible without their combination; and with guidance from a conductor, the sections remain balanced for full effect. The conductor holds the most important role of an orchestra, keeping time and bringing in all different parts to ensure harmony; with that role, it is only fitting that the brush strokes forming the orchestra revolve around the conductor in *Rehearsal of the Pasdeloup Orchestra at the Cirque d'Hiver*.

To attempt to create clarity out of confusion and move from images of *Splendid* to *Rehearsal of the Pasdeloup Orchestra at the Cirque d'Hiver*, the American health care system has turned to the courts as adjudicators for medical decision-making; judges sit as conductors of the orchestra of health care. For cases where patients are incompetent, the court has established that patients still have the legal right to autonomy in decision-making, although their autonomy might be more difficult to ascertain: "the recognition of [a general right in all persons to refuse medical treatment in appropriate circumstances] must extend to the case of the incompetent, as well as a competent patient because of the value of human dignity extends to both."[7] The role of the court, then, has become to follow the English doctrine Ex parte Whitebread and "don the mental mantle of the incompetent" to help identify the best interest of the patients in these cases.[8]

Legal cases of first impression such as Quinlan establish standards that limit the necessity for other prolonged legal battles in similar cases. The Quinlan case created the 'reasonable person' standard to identify what an incompetent patient would want, a "principle that allows a surrogate decision-maker to attempt to establish, with as much accuracy as possible, what decision an incompetent patient would make if he or she were competent to do so."[9] Another case of incompetency, Mr. Saikewicz, a sixty-seven-year-old man who was profoundly mentally retarded and needed treatment for leukemia, set a standard of substituted judgment for a court to "substitut[e] itself nearly as possible for the incompetent, and acting on the same motives and considerations as would have moved him."[10] These standards act as precedent for other legal cases regarding the treatment of incompetent patients, allowing for clear consensus amidst overlapping acrylic paint and ink perspectives.

Despite courts' concise conclusions about medical cases, many question whether courts are the appropriate conductor for medical decision-making. When asked whether she believed that her husband's case to remove a gastrostomy tube was best handled in the legal system, Mrs. Brophy, the wife of a firefighter who persisted in a vegetative state for three and a half years, stated that she thought the courts were the worst place to make medical treatment decisions due to the pain and suffering of the family during that elongated legal process, which for her took years.[11] Mrs. Brophy's sentiments have been echoed by physicians, family members, and even judges alike in different situations. As Judge Warren Burger stated in his dissent in *Georgetown v. Jones*, a case about request for a blood transfusion for a Jehovah's Witness, "There are myriads of problems and troubles which judges are powerless to solve; and this is as it should be. Some matters of essentially private concern and others of enormous public concern, are beyond the reach of judges."[12] Because of the grave importance of medical decisions, lack of medical knowledge of judges, and minimal state interest in private decisions, some consider medical cases, particularly cases where the patient's wishes cannot be clearly ascertained through competency, instances in which the law has no place.

In some cases, judges have created controversy in medical decisions for the incompetent by relying on their beliefs rather than medical information, such as in the probate court decision of the Saikewicz case when Judge Jekamonski ruled based on what his own wishes would be in the situation: "I feel that if I had a serious disease and with treatment I could live another five or eight years or ten years, whatever I'd rather take the treatment than just take the chance of dying tomorrow or next week."[13] By ruling based on opinion without consideration of Saikewicz's profoundly mentally-incompetent state or the medical facts arguing that Saikewicz will never see his treatment competently, judges such as Jekamonski step outside of their assigned role, which is clearly not in the best medical interest of the patient.

More importantly, the use of the legal system to resolve medical disputes conflates the law with morality and pits physicians and families against each other instead of promoting a collaborative relationship for the benefit of the patient. Richard McCormick argues that the law and legal entities are one of the five main factors pushing bioethics into oblivion. He, quoting Gilbert Meilander, states that "if...we understand the point of law to be chiefly the empowerment of self-defining private choice, and if moral discussion has been folded into discussion of what the law should be, we have effectively eliminated from public consideration a wide range of moral concerns."[14] By limiting discussion to the legal framework of decisions, ethical issues such as human dignity are ignored, and standards reject these moral influences. At the same time, since the legal system requires two sides for debate and allows for continual appeal of cases, the legal authority of courts has isolated physicians and families from discussing non-legal ethics or even collaborating on general medical treatment. Legal involvement in health care disputes has only strained an already broken physician-patient relationship, or in this case physician-family relationship. While Jonsen argues that the best outcome for the patient requires such teamwork: "Doctor and patient, each with their own needs, desires, capabilities, must find those principles that allow them to coalesce into a helping, healing alliance to achieve a common goal."[15]

While the American health care system has chosen the court system as a conductor to help harness decision-making for the incompetent from controlled chaos, the correct role of an arbitrary legal entity in moral and ethical decision-making remains unclear. Standards set by the courts have established legal guidelines for subsequent cases, such as in Quinlan and Saikewicz. But if these cases are inherently ethical, do judges have the authority to make moral decisions?

No matter the answer to this question, the court remains the current final authority in American health care, although ethics committees, established in the Quinlan case, are beginning to oversee increasing numbers of cases in hospital settings.[16] One conductor, albeit a potentially poor conductor, places medical decision-making for the incompetent somewhere between *Splendid*'s chaotic web and *Rehearsal of the Pasdeloup Orchestra at the Cirque d'Hiver*'s rotating symphony. Luckily, however, it is only rehearsal.

Splendid
Sinique Smith, 2014

Rehearsal of the Parsdeloup Orchestra at the Cirque d'Hiver
John Singer Sargent, 1879-80

ENDNOTES

1. J. Stuart Mill, "On Liberty," (1869).

2. "Responsibility for the Decision."

3. Ibid.

4. R. Munson, "Karen Quinlan: The Debate Begins," in 5. Intervention and Reflection: Basic Issues in Bioethics (Boston: Wadsworth, Cengage Learning; 2012): 190–192.

5. A.R. Jonsen, R.M. Veatch, L. Walters, "Reexamining the Role of Traditional Moral Distinctions," in Source Book in Bioethics: A Documentary History (Washington: Georgetown University Press, 1998): 169–178.

6. The Sacred Congregation for the Doctrine of the Faith, "Declaration on Euthanasia," (Vatican City: 1980).

7. Superintendent of Belchertown v. Saikewicz (Supreme Judicial Court) (1977).

8. Ibid.

9. "Doctrine of Substituted Judgment Law"

10. Superintendent of Belchertown v. Saikewicz (Supreme Judicial Court) (1977).

11. In Class Lecture, Questions with Mrs. Brophy (04/05/2016)

12. Application of President and Directors of Georgetown College, 331 F. 2d 1000 (D.C. Cir. 1964).

13. Belchertown v. Saikewicz, 370 N.E. 2d 417 (Probate Court) (1976).

14. R. McCormick, "Bioethics: A Moral Vacuum?" America (May 1, 1999)

15. A. Jonsen, "Medical Ethics and Research Ethics: The Role of 'Autonomy' Revisited." (November 14-15, 2008): 1–5.
16. R. Munson, "Karen Quinlan: The Debate Begins," in Intervention and Reflection: Basic Issues in Bioethics (Boston: Wadsworth, Cengage Learning; 2012): 190–192.