

Disputing Parental Judgment in a Case of Dialysis

In cases where a parent is denying life-saving medical treatment, physician paternalism can step in to help provide the proper care to the patient.

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Rachel needs medical treatment for pyelonephritis. Currently, Rachel lives in a group home where she enjoys listening to music, looking at magazines, and socializing with the staff and other residents. She manages her own personal hygiene and engages in other activities of daily living. Rachel also holds down a job at a local publishing workshop where she collates, creates templates, and stuffs envelopes. She works independently, and her employer is very satisfied with her work. She is able to communicate her wants and needs as well as answer a telephone appropriately.

However, Rachel has never been judged competent to manage her personal or financial affairs or provide informed consent for any medical treatment. She is a 33-year-old woman with Down syndrome. Due to the diminished level of Rachel's mental functioning, her mother was appointed her legal guardian. Throughout her life, Rachel has required various degrees of medical attention, from treatment with antibiotics to surgery that required significant patient compliance during intensive rehabilitation.

Recently, a new medical issue has surfaced. As a result of her chronic pyelonephritis, Rachel's kidneys have begun to fail. She needs life-long hemodialysis in order to stave off uremia and ultimately death. This treatment requires that she undergo a minor surgical procedure for the creation of a permanent, high-flow arteriovenous fistula for hemodialysis access. Dialysis would then require Rachel's cooperation for long periods of time, sitting while blood is siphoned to the dialysis machine and returned to her body. Such treatments usually last approximately 3 hours and may be required as often as 3 times a week.

What is usually considered routine therapy for patients in renal failure is now the focus of a vehement dispute. This dispute arose when Rachel's mother refused to give consent for her daughter to receive this life-saving treatment. Based on concerns that her daughter would not be able to understand the need to sit still during the dialysis treatments or the need for the repetitive pain inflicted by sticking her with needles 3 times every week, Rachel's mother felt that hemodialysis would essentially result in emotional torture for her daughter. Rachel's hemodialysis director contested her mother's decision, and a guardian ad litem was appointed for Rachel by the court.

Rachel's need for dialysis is urgent. She retains an estimated 10 percent of her renal function and will certainly die within the next year if she is not dialyzed. With treatment, Rachel could enjoy 10 to 20 years of "quality life." Rachel's physicians, as well as the hemodialysis center director, all of whom have significant experience treating mentally handicapped patients, agree that Rachel is a good candidate for hemodialysis and would be able to comply with the treatment regimen.

Legal Analysis

The above facts are adapted from a case in which a state court of appeals refused to allow a guardian to withhold consent for life-saving hemodialysis of a ward¹. This case lies at the crossroads of medicine and the law, and it raises several critical questions about the law's response to paternalism in medicine.

Patient Autonomy vs Physician Paternalism

Over a century ago, U.S. law responded to the "problem" of physician-directed care. The law's first response was granting the right to refuse medical care. "There is implicit recognition in the law...that a person has a strong interest in being free from nonconsensual invasion of his bodily integrity. In short, the law recognizes the individual interest in preserving the inviolability of his person"². This right to bodily integrity extends to physicians attempting to implement medical therapy on a patient. In other words, patient rights include a right to refusal of treatment.

To ensure the right of bodily integrity as well as to combat paternalism in medicine, the law imposes a burden on the clinician to obtain informed consent. This requires physicians to "communicate material information" to their patients. Two standards have emerged for defining what information qualifies as material.

Traditionally, courts asked what a reasonable physician would have disclosed under the circumstances. With time, this "professional standard" came under criticism for its excessive paternalism and the effective immunity that it granted to defendants in medical malpractice cases.

As a result, almost half of the states have shifted to a "patient standard" of informed consent. Under the patient standard for defining materiality, many courts use an objective test, asking whether a reasonable person would regard the information as important³.

The combination of these 2 rights, informed consent and refusal of treatment, allows every competent adult "to forgo treatment, or even cure, if it entails what for him or her are intolerable consequences or risks, however unwise his sense of values may be in the eyes of the medical profession"⁴. Knowing exercise of this right requires knowledge of the available options and the risks attendant on each⁵.

Patients Who Are Declared Incompetent

Little controversy exists in the importance of the right to refuse medical treatment and to informed consent. However, these legal doctrines cease to operate as effective safeguards when faced with a patient who has been declared legally incompetent. As a preliminary matter, it is necessary to address the meaning of "competence." Generally, "competence" is defined as the "ability to understand problems and make decisions"⁶. If this case were brought before the court in the 1970s or earlier, the issue of competence probably would not even have arisen. Then, courts presumed "and, in many states, the law was, that institutionalization was equivalent to a finding of legal incompetency. By 1970, however, this notion of merging the concepts of institutionalization and incompetency had survived in only a handful of jurisdictions and had been specifically rejected in many others"⁷. Today, virtually every state has an explicit provision to the effect that institutionalization does not affect competency, much less create a presumption of incompetency. (The problems associated with the subjectivity in the law, as illustrated here by the changing legal lexicon, will be addressed later.)

Rachel, who has been declared incompetent, needs others to make decisions for her in order to successfully adapt and thrive. Her guardian made the decision that she would live in a group home, presumably

someone found Rachel the job at the publishing shop, and someone is making daily financial decisions on her behalf.

Rachel, however, is far from being in a vegetative state: she possesses the ability to communicate via speech and gestures, answers the telephone appropriately, and has actively cooperated with every dietary and medical intervention to date. These factors indicate that Rachel comprehends basic ideas and is able to communicate her wants; however, there is no record of her wishes in the probate court's record. In fact the only indication of her desires is the picture painted circumstantially—Rachel is generally a happy woman who enjoys her job. She also participates in outside activities that bring her joy. Rachel, according to the record, is not a morose, hapless person without desire to continue living.

To protect the limited capacity she does possess, the court engages in a "substituted judgment" inquiry. "Substituted judgment" (or an equivalent variant depending on the jurisdiction) is an exercise by which the court "does not decide what is necessarily the best decision but rather what decision would be made by the incompetent person [here, Rachel] if she were competent"⁸.

In making this determination, the jurist must first investigate factors specific to Rachel's particular situation including expressed preferences, religious convictions, any impact on her family, likelihood of adverse side effects from treatment, consequences of refusing treatment, and Rachel's present and future incompetence must be investigated. Then the jurist must consider countervailing state interests such as the preservation of life, protection of innocents, prevention of suicide, and the maintenance of the ethical integrity of the medical profession⁸. But does the "substituted judgment" inquiry really address the patient's desires while minimizing paternalism?

The substituted judgment inquiry is really a euphemism for judicial decision making because there is no meaningful way by which to prioritize these considerations. For example, are the state's interests more important than the patient-specific concerns? The courts have not addressed this question. In the 1993 case on which this analysis is based, the court made a futile attempt to address this concern, stating that factors relating to the patient's situation and preferences should be paramount. In effect, the court tried to have it both ways—essentially applying the substituted judgment test to determine what the individual *would* have wanted if she or he were competent; while simultaneously giving great weight to the preferences expressed by the incompetent patient. Ultimately the appellate court remanded this case to the probate court for further proceedings to determine Rachel's desires and her ability to understand the need for dialysis.

The judiciary is inherently ill equipped to manage medical decision making. First, by involving itself in cases of medical decision making, the court substitutes its judgment for sound medical judgment. Although guided by physician testimony, courts ultimately deprive the incompetent patients of the advantages afforded by the medical team's judgment, imposing a court's supervening decision. Just as there can be no question that a court is far better positioned to rule on statutory matters, there is no disputing that the health care team has superior knowledge and experience making medical decisions.

Generally, giving patients a voice in managing their health care decisions is good practice. However, when confronted with a patient who is legally incapable of partnering with the physician in making health care decisions, the question of who ultimately should make medical choices arises. The law proposes that legal guardians should step into the shoes of the patient and control the patient's treatment. However, as in Rachel's case, guardians, even when appointed by the court, do not always act in the best interest of the ward. The court acts as a safety net when there is conflict between the physician and the guardian. However, as explained earlier, a court is not the best forum to make such decisions. So, who should partner with the physician of a patient who is incompetent?

An obvious solution would be to consult with those who know the patient well and are knowledgeable about health care. Here, although Rachel's mother presumably knows Rachel well, she is not knowledgeable in medicine. Rather, it may be Rachel's longtime physician who knows Rachel best, has his patient's best interests in mind, and understands medicine. In fact, Rachel's physician even consulted with a hemodialysis expert to ensure that a patient with Down syndrome could handle such treatments. Here, medical paternalism, or at least physician advocacy, saved Rachel's life. Without the vehement objections from her physician as well as his faithful advocacy through the appellate process, Rachel's desires would not have been addressed and her life, prematurely and unnecessarily ended. In the case of incompetent patients, it makes sense not only to allow, but to encourage physician-directed decision making.

References

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5. *Canterbury v Spence*. 150 US App DC 263; 464 F2d 772, 780, aff'd. 409 US 1064. *Cobbs v Grant*. 502 P 2d 1:9-10 (Cal 1972).
6. *Blacks Law Dictionary*. 7th ed. 1999:278.
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