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Health law

Limiting parents' rights in medical decision making

by Lee Black, LLM

The law's inquiry into parental competence to provide medical care for a child does not stop at assessing their physical and mental ability to do so; it also examines their willingness to make medically appropriate decisions. The decision of a physically and mentally competent parent to pursue a particular path of treatment may, for example, not accord with the best interests of the child, particularly if a child is not of an age where he or she can contribute to the process. Parents have a legal obligation to refrain from actions that may harm their child. Medical decision making, though, has a certain ambiguity—when does a particular choice indicate that the parent is unable to decide on appropriate care? Religious objections to treatment have a long history of acceptance and, while not absolute, can at times be codified into law [1]. Objections motivated by other beliefs may not receive the same protections and may cause parental objection to specific treatment to be overturned by a court or other authority with more ease than objections based on religious beliefs.

Religious objections

The Supreme Court of the United States has long upheld the right of parents to make decisions for their children based on religious grounds. Generally, when the physical or mental health of the child is not at stake, states and courts defer to the decisions of the parents. For medical decisions, mental or physical health will always be at stake, so a different balancing process must be employed to ensure that the state carries out its duty to protect its citizens but does not infringe on the rights granted to individuals by the First Amendment to the Constitution.

When attempting to declare a given medical treatment decision inappropriate, the state has a high burden of proof because of the great value placed on autonomous parental decision making. The court must weigh the rights of a parent against the interests of the child. One important factor in this process is the expected outcome of the illness or disease: if the proposed medical treatment has a good chance of success and the predicted outcome without treatment is death, courts are more likely to intervene and overrule parental decisions; if the proposed medical treatment does not have a high likelihood of success or the predicted outcome is not death, courts frequently uphold the decision of parents. Generally, it is only when the child's life is at risk that the weighing of interests favors the child and the government authority that is asserting the child's rights.

In one litigated case of religious objections to care by Christian Scientists, the interests of the parents, the child and the state were weighed with consideration of a state law that permitted medical decision making to be influenced by religious doctrine. The Supreme Court of Delaware in *Newmark v. Williams* landed on the side of the parents. The child in *Newmark* was diagnosed with Burkitt's lymphoma and was given a 40 percent chance of survival if he obtained chemotherapy treatments. His parents decided that, rather than allowing an uncertain and painful medical treatment, they would seek treatment through their church [2]. The state objected and filed for temporary custody of the child.

The court determined that the parents were within their rights to forgo the treatment. According to the court,

...the spiritual treatment exemptions reflect, in part, “the policy of this State with respect to the quality of life” a desperately ill child might have in the caring and loving atmosphere of his or her family, versus the sterile hospital environment demanded by physicians seeking to prescribe excruciating, and life-threatening, treatments of doubtful efficacy [3].

The determining factor was that the treatment proposed by the child's physician had only a 40 percent chance of success. From the court's discussion of other legal precedents, if a treatment was more likely to succeed than fail (i.e., had greater than 50 percent chance of success), the state could be justified in gaining custody of a child to obtain medical treatment over the religious objections of his or her parents, although the court made no definitive statement on this matter.

In a more recent case, the Court of Civil Appeals of Oklahoma came to a different conclusion based on a set of facts much more favorable to the state. *In the Matter of D.R.*, the child suffered from seizure activity and developmental difficulties. While in physical therapy to address these problems, she experienced a severe seizure, after which her parents discontinued therapy and sought no other treatment. The state intervened, alleging medical neglect by the parents because the child's condition was potentially life-threatening.

The court decided in favor of the state based on the severity of the medical problem, the likelihood of success of the proposed treatment and the limited potential harm of the treatment. It was “well-settled that the state may order medical treatment for a nonlife threatening condition, notwithstanding the objection of the parents on religious grounds, if the treatment will, in all likelihood, temporarily or permanently solve a substantial medical problem” [4]. The court recognized that the state could not order treatment over religious objection of the parents if the treatment was “risky, extremely invasive, toxic with many side effects, and/or offers a low chance of success” [5]. This decision, consistent with *Newmark*, illustrates the difficulties in determining who should make medical decisions for a child.

Nonreligious objections

Religious objection has a firm foundation in the Constitution and legal precedent. It

is much more difficult for courts to justify parental refusal of treatment for reasons not based in recognized religion (a somewhat arbitrary distinction, but consistently used). For example, if a parent prevented needed care because of a fear of nonexistent risks, the state would be able to intervene with little opposition by courts. Parents have more flexibility in choosing among different treatments that all have some scientific validity; they need not choose the best available treatment. The caveat here is what constitutes valid treatment—courts do not always agree on this.

For decades, laetrile, a chemical compound found in various foods, has been considered by some to be an effective form of cancer treatment. Mainstream medicine has never embraced laetrile use, and there have been no clinical trials of its efficacy [6]. Yet, within a month two courts in the Northeast decided cases based on the use of laetrile and metabolic therapy and came to very different conclusions about its use.

The case of Joseph Hofbauer in New York concerned the definition of “neglected child” [7]. Joseph had Hodgkin’s disease, and his physician recommended that he be seen by a specialist for further treatment that could include radiation or chemotherapy. Joseph’s parents rejected the recommendation and took him to Jamaica where he received a course of metabolic therapy that included the use of laetrile. After his return to the U.S., the state sought to remove Joseph from the custody of his parents on the grounds that failure to enroll him in conventional treatments constituted neglect. A court order authorized continued treatment with metabolic therapy on the condition that Joseph be monitored by a second physician.

At trial, there was voluminous testimony concerning treatments for cancer. Physicians for the state testified that metabolic therapy was inadequate and ineffective for the treatment of Hodgkin’s disease. Physicians for the parents testified that metabolic therapy was beneficial and effective, although they did not preclude the use of conventional treatments that the parents sought to avoid. A scientist testified to an animal study conducted on mice showing the effectiveness of laetrile and other substances. Both sides admitted to the dangerous potential side effects of conventional treatments.

The court began by noting that the statute pertaining to adequate medical care for children required a parent to “entrust the child’s care to that of a physician when such course would be undertaken by an ordinarily prudent and loving parent ‘solicitous for the welfare of his child and anxious to promote (the child’s) recovery’” [8]. Parents can rely on the advice of licensed physicians, because those physicians are “recognized by the State as capable of exercising acceptable clinical judgment” [9]. The question most important to this court was whether the parents provided an acceptable course of care in light of surrounding circumstances. The court determined that the parents were justified in their concern over conventional treatments, that there was medical proof of the effectiveness of laetrile and that metabolic therapy had fewer risks than radiation or chemotherapy. Therefore, Joseph was not neglected within the meaning of the statute.

A month after the New York decision, Massachusetts had occasion to answer the same question: was laetrile appropriate medical treatment? In *Custody of a Minor*, a three-year-old boy suffered from acute lymphocytic leukemia [10]. An earlier court decision had ordered that the child undergo chemotherapy, which was successfully completed. Thereafter, his parents discontinued his medications and the leukemia recurred. The parents sought to supplement their child's chemotherapy with metabolic therapy, including laetrile.

Both the parents and the state introduced expert testimony pertaining to the safety and efficacy of laetrile. None of the parents' experts claimed expertise in the area of blood diseases or leukemia. The state presented various experts in blood diseases, including the child's physician. At an earlier hearing, a judge had concluded that "not only are the assertions concerning metabolic therapy's alleged palliative effect unconfirmed by any well-documented evidence, but there are several alternative explanations for this observed phenomenon" [11].

The court found that the use of laetrile was potentially harmful to the child because of the possibility that it would interfere with chemotherapy and because it posed a risk of cyanide poisoning. The court also decided that "family autonomy is not absolute, and may be limited where, as here, it appears that parental decisions will jeopardize the health or safety of a child" [12]. The court determined that the use of laetrile in this specific case was "not consistent with good medical practice," but it did not address the use of laetrile in all circumstances, drawing a careful distinction with *Hofbauer* by noting the additional testimony of laetrile's possible effectiveness and the different type of cancer at issue in that case.

Interpreting the courts' rulings

The end result of a court battle over the provision of medical treatment depends on the type of objection—religious or secular, the proposed treatment and the prognosis for survival with and without treatment. Religious objection to standard medical therapy is often legally valid when the treatment is more likely to fail than succeed. Respect for religion has forced courts to recognize that medical decisions are not always scientific—many people rely on faith to heal them. On the other hand, the right to refuse treatment based on religious objection is not absolute. In cases where adherence to religious tenets that prohibit standard, life-saving care, e.g., blood transfusion, would almost certainly lead to a child's death, the courts have decided that parents cannot make martyrs of children who are too young to have consented to embrace the faith.

Objection for other reasons leads to more varied court decisions, but these objections can be overruled more easily than faith-based objections. Parents cannot refuse all medical treatment as they can if the objection is based on recognized religious doctrine. If alternatives may be successful and are less invasive than a risky standard medical treatment, courts may defer to parents. If the alternative treatment has no scientific merit, courts will most likely prevent parents from standing in the way of their child's health.

It is important to remember that legal competence to make medical decisions for children is not just about physical or mental capacity; it is also about making appropriate, best-interest decisions. Medical neglect statutes examine whether appropriate care was provided, not how it was provided. A parent who refuses care based on an objection to treatment, whatever the basis, is just as likely to have the state intervene to make medical decisions as a parent who is not physically able to provide care or not mentally capable of making decisions.

Notes and References

1. For example, the Illinois Compiled Statutes define “neglected child” to exclude a child whose “parent or other person responsible for his or her welfare depends upon spiritual means through prayer alone for the treatment or cure of disease or remedial care...” 325 ILCS 5/3. (2006).
2. *Newmark v Williams*, 588 A2d 1108 (Del 1990).
3. *Newmark* at 1112.
4. *In the Matter of D.R.*, 20 P3d 166, 169 (Ct App Okla 2001).
5. *In the Matter of D.R.*, at 170.
6. National Cancer Institute. Questions and answers about laetrile/amygdalin. Available at: http://www.cancer.gov/cancertopics/pdg/cam/laetrile/patient/Page2#Section_23. Accessed August 24, 2006.
7. *In the Matter of Joseph Hofbauer*, 393 NE2d 1009 (NY 1979).
8. *In the Matter of Joseph Hofbauer*, at 1013.
9. *In the Matter of Joseph Hofbauer*, at 1014.
10. *Custody of a Minor*, 393 NE2d 836 (Mass 1979).
11. *Custody of a Minor*, at 841.
12. *Custody of a Minor*, at 843.

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