Law, Ethics, and Gender

Compelled Organ Donation
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ABSTRACT
Along with ethical considerations, compelling an individual to donate organs, tissues, or bodily fluids brings several legal doctrines into conflict. The privacy of one's body is generally considered sacrosanct by American courts, which have upheld a competent adult's right to refuse medical procedures, even in cases when they are necessary to save the life of another. Although medical and legal communities stress "respect for the individual" as being paramount under American jurisprudential principles, the doctrine of "substituted judgment" permits a court to act (for example, by consenting to organ donation) on behalf of an incompetent individual or child. Parents also have the right to cause a child to "donate" an organ, and although a means exists by which the child can refuse, this may not be realistically feasible for young children. The revised Uniform Anatomical Gift Act of 2006, while clarifying issues of who may make organ donation decisions, does not resolve all the practical issues of compelled organ donation for minors. (Gend Med. 2009;6:516–520) © 2009 Excerpta Medica Inc.

INTRODUCTION
"The people who voluntarily donate an organ to a relative are sometimes subject to greater coercion than those who sell their organs, because of internal pressure and pressure from other family members to save the loved one."1

In the popular novel My Sister's Keeper,2 the parents of a terminally ill child decide to have another baby—one who will be used to keep the elder child alive. The parents use cutting-edge biotechnology to conceive a child, Anna, who spends her first decade of life “donating” her umbilical cord, blood, bone marrow, and platelets to her elder sister. At the age of 13, when she is asked to donate one of her kidneys, Anna seeks judicial intervention to allow her to make her own medical decisions. The story in My Sister's Keeper is fictional, but the technology used to create so-called “savior siblings” is real—and has been used for exactly that purpose. The use of such savior siblings raises legal and ethical questions, some of which this article seeks to identify.
COMPELLED ORGAN DONATION AND THE COURTS

Compelling another person to “donate” organs, tissues, or bodily fluids brings several legal doctrines into conflict. Among the most basic of these doctrines is the right of personal autonomy—the right to control what is done to one’s body. The privacy of one’s body is generally held as sacrosanct by courts, even when harm might come to others.

American courts have upheld a competent adult’s right to refuse medical procedures, including cases when they are necessary to save the life of another. Among the most well known of these cases is that of Baby Boy Doe from Illinois,\(^5\) in which a 35-week fetus was found to be receiving insufficient oxygen because of a problem with the placenta. Physicians recommended immediate delivery by cesarean section (or induced labor).

However, the pregnant woman refused because of her personal religious beliefs, even though she was warned that waiting would greatly jeopardize the fetus. Thus began a series of emergency legal proceedings, in which state attorneys sought an order from the court, forcing the woman to undergo an immediate cesarean section to protect the fetus. The courts rejected the application for such an order, noting that adults have the right to refuse medical treatment and that a “woman’s competent choice to refuse medical treatment as invasive as a cesarean section during pregnancy must be honored, even in circumstances where the choice may be harmful to her fetus.”

McFall v Shimp

Courts have also held that competent adults may refuse to donate organs, despite the harm that might befall the intended recipient. In the case of McFall v Shimp,\(^4\) plaintiff Robert McFall had aplastic anemia—a rare bone-marrow disease—and would die unless he found a bone-marrow donor. After a thorough search, the only person found with suitable marrow to donate was Robert Shimp, the plaintiff’s cousin. Even though the cousins were good friends, Shimp refused to donate, and McFall went to court to try to force him to do so.\(^5\) While the view of the court was that Shimp’s actions were “morally indefensible,” it stressed “respect for the individual” as being paramount under American jurisprudential principles. The court continued, “For a society which respects the rights of one individual, to sink its teeth into the jugular vein or neck of one of its members and suck from it sustenance for another member, is revolting to our hard-wrought concepts of jurisprudence.” (In its decision, the McFall court cited the common law rule that “one human being is under no legal compulsion to give aid or to take action to save another human being or to rescue.” First-year law students are often told the hypothetical story of a hiker encountering an injured hiker on a wooded trail. The able-bodied hiker has no obligation under the law to assist the fallen. Indeed, even a request to borrow a cell phone to make an emergency call typically can be rebuffed without legal punishment.)

Strunk v Strunk and Hart v Brown

Contrast the McFall decision with the law concerning incompetents and minors. The same “invasions” that have been rejected when proposed to be performed on competent adults have been permitted in incompetents and minors. In 1969, the highest court in Kentucky became the first American court to address whether a parent could authorize removal of one child’s kidney and surrender it to another.\(^5\) In the case of Strunk v Strunk,\(^6\) Arthur and Ava Strunk were the parents of 2 sons in their late 20s. Tommy Strunk was a married and employed 28-year-old with chronic glomerular nephritis, a fatal kidney disease. Jerry Strunk, age 27, was mentally incompetent with the capacity of a 6-year-old, had a severe speech impediment, and was confined to a state hospital as a ward of the state. All family members were tested, and Jerry was the only one who met all the donor requirements. Ava petitioned the court to go forward with the transplant. The state department of mental health also recommended going forward with the surgery, in part because of Tommy’s importance to Jerry’s development and happiness. The Kentucky high court approved the procedure, using the centuries-old doctrine of “substituted judgment” that permits a court to act
on behalf of an incompetent to reach a decision that the incompetent presumably would have made had he been able to do so.

A few years later, in *Hart v Brown*, parents of identical twin girls, aged 7 years and 10 months, requested, on recommendation of their physicians, that a hospital transplant a kidney from the healthy twin to the ailing one, who had hemolytic uremic syndrome. The sick twin would likely die if a transplant was not performed. The hospital refused to undertake the surgery unless a court declared that the parents (or some other guardian) had the right to give consent for the operation on behalf of the minors. The court appointed a guardian to represent each child. To the extent the transplant was explained to the donor child, she expressed a desire to donate her kidney so that her sister would return to her. All the testimony (from physicians, guardians, parents, and clergy) was in favor of the surgery. The court, using its authority under the substituted judgment theory, ruled that in light of these particular facts, the parents could give consent for the 2 children.

In *Strunk v Strunk* and *Hart v Brown*, all parties to each case, including the guardians for the donor, wanted the operation to go forward, and the courts used the substituted judgment rule to justify their decisions. Both of the donees in those cases were siblings of the donors, and the court cited the fact that the donor would fare better if the donee were alive. In cases where the same request is made of competent adults who do not want to donate, that rejection is respected by the courts. This disparate treatment creates questions as to whether there is more under the surface than just the application of the legal principles relied on by the parties and the courts. It may be that courts are less likely to use substituted judgment to prevent a mentally incompetent individual from donating an organ when the surgery would benefit an able-bodied individual.

*Curran v Bosze*

In *Curran v Bosze*, the Illinois Supreme Court carried forward the reasoning in *McFall* to hold that altruism cannot be compelled by a relative. In this case, Tamas Bosze sought to compel his 3-year-old twins to undergo blood testing to determine if they were potential bone-marrow donors for their half-brother, Bosze's 12-year-old son Jean-Pierre, who had acute undifferentiated leukemia. Bosze did not have custody of the twins; their mother, Nancy Curran, did. As their legal guardian, she refused to consent to the procedure, and Bosze went to court to try to overrule her.

The lower court ruled that the blood test and possible bone-marrow transplant would be an invasion of the twins' privacy. The court chose not to use the substituted judgment line of reasoning to determine what the twins would have thought if they had the capacity to consent. The court held that a parent or guardian may give consent on behalf of a minor child to donate bone marrow to a sibling, but only when doing so would be in the minor's best interest. The court established 3 factors that had to be met to make the best-interest determination: (1) the consenting parent must be informed of the risks and benefits of the procedure; (2) there must be emotional support available to the child from the people who take care of the child; and (3) there must be an existing close relationship between the donor and recipient. Because the twins' mother, who was the only caregiver they had ever known, did not consent, the court questioned whether the requisite emotional support would be present if the twins were forced to undergo bone-marrow harvesting. Additionally, the court stressed the importance of a family relationship between donor and donee. “The psychological benefit is grounded firmly in the fact that the donor and recipient are known to each other as family.” In this case, the twins had met Jean-Pierre twice, for 2 hours each time, and did not know he was their brother. The Illinois high court affirmed the lower court's denial of Bosze's attempt to compel the twins to undergo the medical procedures.

**The Nash Family**

In all of the previously mentioned cases, the children were identified as being potential donors well after their births. But what if parents of a sick child choose to have another baby—for the purpose of using that child as a donor for the ill elder
sibling? Such a situation provided the compelling drama in the bestseller *My Sister’s Keeper*, but has also been played out in real life.

Molly Nash was born with Fanconi anemia, a rare genetic disease, and had multiple birth defects. Around the age of 5, doctors recognized that she needed a bone-marrow transplant to survive, but a suitable donor could not be found: Molly had no siblings and her parents were not suitable donors. So her parents, who already wanted a larger family, decided to have a second child, whose umbilical cord blood could be used to try to save Molly.5,9,10

Physicians used in vitro fertilization to create multiple embryos for the Nashes. The embryos then went through 2 stages of preimplantation genetic diagnosis (PGD). First, the embryos were screened for Fanconi anemia. Those embryos that did not have genetic markers for the disease were then tested again to determine if they were genetically compatible with Molly. In a second round of PGD testing, the embryos were human leukocyte antigen–matched to Molly’s blood cell type. Following the second PGD test, an embryo was implanted in Lisa Nash, and 9 months later, Adam was born. A month after his birth, Molly received Adam’s umbilical cord blood containing the hematopoietic stem cells that repopulated her bone marrow with healthy blood cell progenitors.

The Nashes are believed to be the first couple to use PGD to create an embryo that could save a sibling’s life.11 The hematopoietic stem cell transplantation procedure using Adam’s umbilical cord blood, which took place in 2000, seems to have been successful. Molly’s bone marrow is now free of Fanconi anemia, although several other health problems remain.10 The Nashes claim that they have no intention of using Adam in the same way that the fictional parents in *My Sister’s Keeper* used Anna. Lisa Nash said, “We decided Adam’s cord blood would be used to attempt to save Molly’s life, but that would be it. He would not be used for his blood, marrow, or organs after he was born.”11 While the Nashes’ discretion may never be tested, the medical and legal communities may not be fully prepared to cope with a set of parents, like those in *My Sister’s Keeper*, who are more willing to use their offspring to save an elder sibling.

**STATUTES**

At the federal level, Congress passed the National Organ Transplant Act (NOTA) in 1984 to outlaw the sale of organs and to develop a national system for organ sharing and the collection of transport data. NOTA led to the establishment of the Organ Procurement and Transplantation Network, a unified transplant network operated (as required by NOTA) by a private nonprofit organization (United Network for Organ Sharing) under federal contract with the Health Resources and Services Administration of the US Department of Health and Human Services (HHS). The HHS Advisory Committee on Organ Transplantation Summary Recommendations to the Secretary, which are guidelines and do not carry the force of law, state that a “person who gives consent to becoming a live organ donor must be competent (possessing decision-making capacity), willing to donate, [and] free from coercion.”12 Because of the lengthy wait for organs on the national donor list, the federal codification of an altruistic system—because payment for organ donation can result in imprisonment—makes it more likely that parents of sick children will consider using “savior siblings.”

The National Conference of Commissioners on Uniform State Laws (NCCUSL) promulgated the revised Uniform Anatomical Gift Act (UAGA) in 2006 after more than 2 years of study as a replacement for the 1968 and 1987 versions of the Act. The original UAGA was promulgated in 1968, shortly after Dr. Christian Barnard successfully transplanted a heart in November 1967. The 1968 UAGA created the power, which previously had not been recognized by the courts, to donate organs, eyes, and tissue in an immediate gift to a known donee or to any donee who might need an organ to survive. It was uniformly adopted nationwide. In 1987, the NCCUSL revised the 1968 UAGA to address changes in circumstances and practice, but it was adopted by only 26 states, and subsequent amendments resulted in less uniformity.
The 2006 UAGA has been adopted by 37 states and the District of Columbia, according to the NCCUSL. Section 4 lists the parties that have the authority to make an anatomical gift before the donor’s death, including “a parent of the donor, if the donor is an unemancipated minor.” The NCCUSL’s commentary to Section 4 clearly states that, “Section 4 expressly empowers an anatomical gift to be made on behalf of an individual by that individual’s agent or a parent, if that individual is an unemancipated minor, or by a guardian.” While Section 4 gives a parent the right to cause a child to “donate” an organ, Section 7 offers a means by which the child can refuse. By signing a record, an individual may refuse to make an anatomical gift of his body parts. The comments to Section 7 note that “Section 7 honors the autonomy of an individual whose body or part might otherwise be the subject of an anatomical gift by empowering the individual to make a refusal. There is no age limitation for an individual to sign a refusal. An individual of any age can do so.”

While a child, in theory, has the right to sign a refusal, the statute seemingly ignores the practicalities. Parents of a minor child, under Section 4, can sign a form to carry out their child’s organ transplant. If the child writes and signs his own record of refusal, the child can refuse to donate his organs. But how does a 3-year-old knowingly sign anything? If the parents wish to compel a 3-year-old to donate bone marrow, unless the child signs his own record of refusal, or the child’s agent (defined as someone “[A] authorized to make health care decisions on the principal’s behalf by a power of attorney for health care; or [B] expressly authorized to make an anatomical gift on the principal’s behalf by any other record signed by the principal”13) or a nonparental guardian intervenes to stop the gift under Section 6 (revoking a gift), there may not be a way under the law to stop the parents from proceeding with the “donation.”

That being said, it may be that the UAGA’s flaws can be dealt with at the hospital level. Hospitals are acutely aware of the ethical and legal issues involved with nonvoluntary organ donation. In the \textit{Strunk}, \textit{Curran}, and \textit{Hart} cases, none of the hospitals would go forward with the procedures without a decision from a court instructing the institution that it was proper to do so. In each of these cases, the court appointed a guardian for the “donor” for the purposes of the litigation. The \textit{guardian ad litem} represents the interests of the minor. This guardian would likely have the authority under the UAGA to prevent a transplant from going forward. Therefore, if a young teenage girl told the doctors that she did not want to donate her kidney, as in \textit{My Sister’s Keeper}, it is at least probable that the hospital would wait until the legal issues were resolved before proceeding. How this would actually work for younger children who are unable to express their desires (or who are more easily manipulated by their parents) is unknown. In those cases, the issues would seem to remain quite real and irresolvable, except on an ad hoc basis.

\textbf{REFERENCES}

12. OrganDonor.gov. US Department of Health and Human Services Advisory Committee on Organ

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