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Review:

My Sister's Keeper: Compelled Donations and a Minor's Right to their Own Body

By: Ayah Elfarra

I. INTRODUCTION: MY SISTER'S KEEPER

"Forget about the fact that the operation is dangerous, or that it would hurt, or that I might just not want to have something cut out of me. But if I only have one kidney, then what happens to me? What if I need it? And am I really never allowed to play sports or be a cheerleader or get pregnant?...What if I just want to live a long time?...Remember how the doctor said if I did the operation, I would have to be careful for the rest of my life?...I don't want to be careful."

My Sister's Keeper is a movie about an 11-year-old girl named Anna Fitzgerald and her terminally ill sister. Anna was a designer baby. She was made in a dish to be spare parts for her sister who suffered from leukemia. Anna's parents genetically created Anna for the purpose of being her sister's savior. Anna's life purpose was to be a "donor child". She began "donating" to her sister from the moment Anna was brought into the world. She donated cord blood as an infant, along with white cell transfusions, bone marrow, and lymphocytes. Anna had eight hospitalizations in eleven years, in addition to six catheterizations, two bone marrow aspirations, and two stem cell purges. She experienced many side effects, including bleeding, infections, and bruising. Anna needed growth hormones, drugs for nausea, opiates for pain, and Ambien for sleep. But that was not where the donations ended. Anna was then asked to donate one of her two kidneys. That was when Anna finally decided that she was done. She found an attorney and sued her parents for the rights to her own body.

Organ donation by living donors presents a unique ethical dilemma, in that physicians must risk the life of a healthy person to save or improve the life of a patient. There are three categories of donations by living persons: first, directed donation to a loved one or friend; second, nondirected donation; and third, directed donation to a stranger. Each type of donation has its own medical concerns; however, the focus of this article is on the first type of donation: directed donation to a loved one or friend.

Intense pressure is placed on people to donate when the donation is directed to a loved one or friend. This pressure makes those who are reluctant feel compelled or obligated to donate. Compelling another person to donate organs, tissues, or bodily fluids brings several legal doctrines into conflict. One of these doctrines is the right to personal autonomy—the right to control what is done to one's body.

II. A MINOR'S RIGHT TO THEIR OWN BODY

"It's against her will, so how does that work? Do you hold her down, or do I?... You gonna take her ankles and I'll take her wrists?... You wanna sedate her? Get handcuffs, tell her we're going to get ice cream again? Because if we do,

every day for the rest of her life she's gonna look at us like we forced her, like we used her. And she'll be right."

Courts have upheld a competent adult's right to refuse medical procedure, even when the procedure is necessary to save the life of another. In *Baby Boy Doe*, a 1994 Illinois Court of Appeals case, a mother refused to have immediate delivery by cesarean section despite the fact that her 35-week fetus was receiving insufficient oxygen. The State's Attorney sought an order from the court that would force the mother to undergo an immediate cesarean section; however, the courts rejected the application. The court held 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. But how does this decision translate into a minor's right to refuse a procedure?

In *Hart v. Brown*, a 1972 Connecticut Supreme Court case, parents of identical twins, about seven years of age, requested that a hospital transplant a kidney from the healthy twin to the sick one. The sick twin would likely die if the transplant were not performed; however, the hospital refused to operate 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. After the transplant was explained to the donor child, she expressed a desire to donate her kidney so that her sister would return to her. In addition to the donor child's desire to donate, the testimony given by the physicians, guardians, parents, and clergy were also in support of the surgery. In coming to their decision, the Connecticut Supreme Court used a substituted judgment line of reasoning where the court determines what the donor child would have thought if they had the capacity to consent. Under these circumstances, the Connecticut Supreme Court held that the parents could give consent for the two children.

III. THE UAGA

In 1968, the original Uniform Anatomical Gift Act (UAGA) was promulgated, creating a power that, at the time, was not yet recognized at common law. The 1968 UAGA created the power to donate organs, eyes, and tissues in an immediate gift to a known donor or to any donor that might need an organ to survive. In 1987, the first revision to UAGA was promulgated; however, only 26 states enacted the 1987 version of the UAGA, resulting in non-uniformity among the states. State amendments to the Act resulted in even more inconsistency in application. In addition to the non-uniformity among the states, there was also non-uniformity between state and federal laws addressing organ donations. Due to the uneven adoption of the 1987 UAGA, numerous amendments over the years in each state, and the inconsistencies between the state and federal laws, the 2006 revision of the UAGA was created.

The UAGA governs organ donations for the purpose of transplantation. Every state in the United States has adopted some form of the UAGA. The 2006 version of the UAGA, the version adopted by the state of Illinois, was created with three main goals. The first goal was to encourage the general public to make more anatomical gifts. The second goal was to strictly honor the wishes of individuals, which includes respecting the right to make or not make anatomical gifts. The third goal was to preserve the current organ donation system because it requires affirmative intent, or

first-person consent, to make an anatomical gift, and also strictly prohibits and harshly punishes the sale and purchase of organs. Sections 4 and 7 of the 2006 UAGA address who can authorize an anatomical gift and how a donor can refuse such a gift.

Section 4 of the 2006 UAGA lists the parties that have the authority to make an anatomical gift before the donor's death. This list includes "a parent of the donor, if the donor is an unemancipated minor." The UAGA does not define an unemancipated minor; accordingly, the phrase is defined by state law. While Section 4 gives a parent the right to have their child donate an organ, Section 7 offers a way for the child to refuse.

According to Section 7, an individual may sign a record refusing to make an anatomical gift of his or her body parts. The comments to Section 7 note that Section 7 honors the autonomy of an individual whose body or body 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, and a refusal can only be made by the individual whose parts are the subject of the refusal. Once a refusal is expressed, an anatomical gift of the individual's body or body part by all other persons is barred. However, it is currently unclear how Section 7 is applied in practice.

IV. APPLICATION

As explained above, Section 7 of the UAGA gives a person of any age the right to refuse a donation which, in theory, would help to prevent compelled donations. However, in practice, this presents a problem: how do we protect children who do not yet have the capacity to refuse?

Each child's capacity to refuse should be evaluated prior to the child's donation. When obtaining a child's capacity to consent, the child's mental capacity is assessed. The same should be assessed in regard to the child's capacity to refuse.

Mental capacity is described as having the ability to reason and deliberate, hold appropriate values and goals, appreciate one's circumstances, understand information one is given, and communicate a choice. Accordingly, prior to any donation, the specific operation should be explained to the child, along with the consequences of refusing or consenting to the donation. After the operation has been explained to the child, a psychological evaluation of the child's understanding should be evaluated. Finally, the child should communicate a choice. The responsibility of assessing the child's capacity to refuse should lie with the hospital, as the hospital would be in the best position to carry out these procedures. When it is determined that a child does not have the capacity to refuse, we should look to the courts.

When a child does not have the capacity to refuse a donation, the operation should be barred until a court order permitting the donation is obtained. The hospital in *Hart v. Brown* refused to operate on the seven-year-old twins 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. In doing so, the Connecticut Supreme Court evaluated what the donor child would have thought if they had the capacity to consent. This is a perfect example of how the courts can help prevent compelled donations.

By applying procedures such as these, we can better ensure that a child's right to their own body is protected.

V. CONCLUSION

"Every procedure had its risks and complications. Anna understood that, she was okay with it." ... "Really?...At five years old."

While Section 7 provides a means for preventing compelled donations on paper, that purpose is not necessarily achieved in practice. The quote above perfectly illustrates this issue. Anna's mother argued that Anna understood the risks and was okay with the donations; however, can a child at the age of five truly understand and consent to such a thing? What about a three-year old? A newborn? If a parent has the authority to consent on behalf of their unemancipated minor and said minor is too young to understand they have the ability to refuse, how is the compelled donation prevented? Who ensures the minor child's rights to their own body is being upheld? Anna was lucky—she sued for the rights to her own body and won. However, her eleven years of "donations" could not be returned. Anna's eleven years of compelled donations should have been prevented. The existence, or lack thereof, of a court order permitting the donation could have prevented Anna's compelled donation. Requiring the hospital to evaluate whether Anna, an unemancipated minor, actually consented to the donation could have prevented a compelled donation. These are ways Anna's rights to her own body could have been protected. Although Anna is just a character in a movie, her experience is one that is all too real and should not be ignored.

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