

UNDERSTANDING THE POSITION OF THE SAVIOR SIBLING:
HOW CAN WE SAVE LIVES AND PROTECT SAVIOR SIBLINGS?

BY

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LIST OF ABBREVIATIONS

ABBREVIATION	MEANING
AAP	AMERICAN ACADEMY OF PEDIATRICS
BM	BONE MARROW
BMT	BONE MARROW TRANSPLANT
HFE ACT	HUMAN FERTILIZATION AND EMBRYOLOGY ACT
HFE AUTHORITY	HUMAN FERTILIZATION AND EMBRYOLOGY AUTHORITY
HLA	HUMAN LEUKOCYTE ANTIGEN
HSC	HEMATOPOIETIC STEM CELL
HSCT	HEMATOPOIETIC STEM CELL TRANSPLANT
HTA	HUMAN TISSUE AUTHORITY
IVF	IN VITRO FERTILIZATION
MPD	MEASURES OF PSYCHOSOCIAL DEVELOPMENT
PGD	PRE-IMPLANTATION GENETIC DIAGNOSIS
UNOS	UNITED NETWORK FOR ORGAN SHARING

ABSTRACT

The purpose of this thesis is to explore the ethics of the process for creating and using savior siblings as genetic material donors. In the past twenty years, use of savior siblings has increased when living donors cannot be located. Traditionally, a savior sibling is a child conceived to provide transplantable genetic material needed by another sibling. This thesis suggests a broader and more useful definition of “savior siblings.” While usage of savior siblings has increased, little research has been done to understand how being a savior sibling influences the psychosocial development of these children. Chapter 1 of this thesis briefly presents the climate surrounding savior siblings and briefly examines some international processes for creating and using savior siblings. Chapter 2 contains a review of existing research regarding savior siblings. Chapter 3 discusses the ethical concerns related to the creation and use of savior siblings. Chapter 4 analyzes two fictional films that present narratives about the dangers of unrestricted savior sibling use. Finally, Chapter 5 reviews and proposes guidelines for reducing trauma associated with serving as a savior sibling.

INTRODUCTION

Isabelle Mason, an African American woman, and Monroe Mason, a Korean American man were married six years ago. Five years ago, Isabelle gave birth to a healthy daughter named Samantha. Samantha lived a rather healthy life until age 4. Suddenly, Isabelle noticed that Samantha's skin was losing its color: white freckles formed on her face, elbows, and hands. Isabelle ignored the freckles, assuming that they were normal blemishes caused by playing outside. Three weeks later, Isabelle and Monroe noticed that their daughter no longer felt the need to eat, and that she bruised easily. The parents took their daughter to the family physician. The physician then referred them to the emergency department at a local hospital.

After some testing, the attending physician delivered the diagnosis of Fanconi anemia, an ailment that interferes with a patient's ability to produce platelets, red blood cells, and white blood cells. The disease prevents cells from repairing themselves because of damaged genes within the cells. Though Samantha's external symptoms appeared minor, the attending physician revealed that the child would require a bone marrow transplant within three years' time or die.

The physician informed Isabelle and Monroe that because their daughter is biracial, the best bone marrow match would be a sibling. Isabelle and Monroe informed their daughter's medical team that Samantha had no siblings, at that time. The Masons reached out extended family and friends to try to find adequate donors but were unsuccessful. Frustrated, the family decided to pursue other options for locating donors – the family searched the Internet. Isabelle and Monroe found articles written by and about other families looking for bone marrow donors for sick children. These

families found donors by conceiving another child who had the same genetic and immunological makeup as their ailing children. The Masons talked with their daughter's treatment team about pursuing this option. The conception of the new child would provide material that could be effective in curing their daughter's anemia. Should the medical team encourage the family to pursue this option? What effect could this decision have on the savior sibling?

Parents decide to have children for many reasons. These reasons may be pragmatic or self-serving: creating closeness between partners, improving one's community standing, creating a child to provide assistance at home, creating the possibility of grandchildren, or anticipating enjoyment from raising the children themselves. Having children in any context has ethical implications regardless of the parents' motives for procreation. While United States case law ensures that parents have the right to procreate on their own terms, the issue of savior siblings presents an unforeseen twist in the reasoning for childbearing. The idea of having a child to help further the interests of the family is one issue; parents may have children so that they will have someone to care for them when they are old or so that children can help one another financially in future. But in either of these cases, the children's conception is justified through a consequentialist evaluation of events. Some time in the distant future, the investment in having children either pays dividends or proves to be a thankless endeavor. However creating a savior sibling entails bringing a child

into the world, assigning him or her a role before birth (a role that he or she will hopefully fulfill and grow out of within the first few years of life), and then finding the child a place in the familial hierarchy later.

In comparison, consider the following example: Farmer Bill has one son and one daughter. Bill cannot afford to hire farm hands to work his land. He and his wife work the land themselves, without heavy machinery because they cannot afford that either. The couple, working together, can barely till ten percent of the land they own. As a result, the family lives near the poverty line. As soon as the children reach an age where they can be helpful in the field, they begin doing simple tasks. When the children are old enough, the children may be required to execute more complicated tasks. With the help of their young children, the parents can till two to three times as much land as before in the same amount of time. Because labor provided by their children is free, the parents keep more of the profits earned from the sale of their crops. The parents realize that as the children grow older, they will be able to do more intensive work. The more children the couple has, the more money the couple will be able to make to care for the family. For families like Bill's, parents ensure that their children survive by having more children.

There are some similarities between the two scenarios: farmers having more children and families with ailing children having more children. Both the savior sibling and the farm-hand child are conceived to help support the familial structure. Siblings ensure the well being of the family by working together toward the common goal of having a better quality of life. Also, both types of children are born into their circumstances and must cope the best each child can. The difference,

however, is the gravity of each child's place in the family. In the farming family, a child unwilling to work in the fields may decide to look for work in another industry. That other job may even be more lucrative than farming. The child can still contribute to the care of his or her siblings and to his or her parents in the household in other ways. A savior sibling, on the other hand, does not have an alternative mode of helping. Either the child donates his or her genetic material or the ailing sibling continues to wait for someone else to make the necessary donation, if that other donation ever materializes. The savior sibling may feel pressured to donate material to his or her ailing sibling because it removes the pains associated with waiting. Clearly the tactic of pressuring an individual would be most effective if directed toward an individual who could understand verbal "persuasion," but what about savior siblings who are so young that they lack the power of language to express dissent?

Before delving into the answer to this question, a clarification in terminology must be made. Traditionally, a savior sibling is a child who is born after a family member has fallen ill. Such children are conceived either naturally or with the assistance of in vitro fertilization. There are, however, two additional groups of children who are used in the same way as the traditional savior sibling, but who do not fall under the traditional definition. This thesis identifies four categories of savior siblings. The first two categories encompass children who are traditionally thought of as savior siblings – created siblings:

1. Younger children who are naturally conceived for the purpose of providing material for an older sibling.

2. Younger children who are conceived using in vitro fertilization (IVF) with pre-implantation genetic diagnosis (PGD) and human leukocyte antigen (HLA) matching. PGD and HLA are means of testing an embryo to ensure that the resulting child is born without his or her sibling's ailment and that the resulting child is a good transplant match for the ailing sibling.

The next two categories encompass the children who do not fit into the traditional definition – pre-existing siblings:

3. Older children who provide genetic material for younger siblings. These children have the power of language and the capacity to contribute to the decision of becoming a donor.
4. Young children who already exist who provide genetic material to a sibling. These children may have minimal or no language skills to be able to contribute to the discussion about becoming a donor.

Category three and four savior siblings are individuals who already exist and occupy a specific niche in their family. Some of these children are able to voice assent and dissent during the decision-making process. In those cases, provision of any genetic material provided by those individuals is more likely to be voluntary, whereas category one and two children are deliberately created to serve as donors and probably will not participate in treatment dialogues.

A terminological problem of describing the harvesting of tissue from incompetent donors concerns referring to the savior sibling's contributions as *donations*. Merriam-Webster's Dictionary defines a *donation* as "the making of a gift

especially to a charity or public institution; a free contribution” (Merriam Webster 2013). Yet young children who provide bone marrow, stem cells, and organs essentially cannot opt out of giving away those pieces of their bodies, and therefore cannot make “donations.” Another lexical folly occurs when describing the savior sibling’s role. Category one and two savior siblings have “savior” as their primary role. In fact, the term *savior* seems to imply an incontrovertible duty the savior sibling has to save the life of the loved one. If this duty to save is taken literally, failure to fulfill it may have the power to create a sense of inferiority in the would-be savior sibling. All in all, the language used to describe savior siblings in this thesis follows the convention created by writers on this topic, but the meaning of the term “savior sibling” in this thesis is not meant to imply a universal duty or responsibility.

Because parents provide parental permission for any tissue recovery procedures to take place and because many savior siblings lack the power of language at the time of transplantation, the donation is essentially compulsory. The donors are unable to weigh in on the decisions about who can have access to their bodies. These two components – that they are to be used to provide immediate genetic assistance and that their assistance is compulsory – make savior sibling creation fundamentally different from other rationales for having children.

While the idea of creating children or using pre-existing children who can save another human being seems like an amazing advancement in medicine, a limited number of studies into the matter indicate that parents and physicians may, in fact, be asking too much of these young individuals. Studies show that almost one-third of children who serve as tissue donors for siblings develop post-traumatic stress

disorder and psychosocial developmental issues as a result of participation. These studies, in essence, suggest that the unregulated savior sibling creation scheme fails to offer adequate protection. Though more research should be done to understand the full extent of the effects that the savior sibling role might have on children, these studies are still quite telling. This thesis (1) explores the process of savior sibling creation and use, (2) discusses some of the ethical concerns related to savior sibling use, and (3) identifies ways the savior sibling process can be structured so that savior siblings are treated fairly and in a way that respects the savior sibling's vulnerabilities.

In Chapter 1, the thesis presents the process of deciding to create and use a savior sibling. This thesis then discusses some of the case law that allows savior sibling creation and use to exist. In Chapter 2, this thesis discusses some of the psychological effects for children who donate organs to siblings. One of the major pitfalls of trying to study the information currently available is the fact that there are so few studies that particularly target savior siblings. As such, this thesis uses the studies in Chapter 2 to draw comparisons to category one and two savior siblings. In Chapter 3, this thesis evaluates some of the ethical concerns surrounding savior siblings and uses interviews from the few savior siblings who have spoken publicly to highlight some of the concerns raised by the use of these children. This thesis also discusses and evaluates these concerns using the ethical framework devised by Gert, Culvert and Clouser (1997, 1-47). In Chapter 4, this thesis discusses two films – *My Sister's Keeper* and *Never Let Me Go*. These films represent worst-case scenarios that may arise if the unregulated savior sibling process continues without

recognizing the information gleaned from studying savior siblings. In Chapter 5, this thesis proposes ways that families and society can approach savior sibling creation and use so that each ailing sibling-savior sibling pairing can accommodate the needs of both children, minimize harms done to savior sibling, and maximize parents' abilities to incorporate a savior child into the family.

CHAPTER 1 – FROM CREATION TO USE: SAVIOR SIBLINGS

The members of the Mason family’s medical team have heard of savior siblings, but their hospital has never been involved in one of these kinds of cases before. The team consults the hospital’s policies regarding treatment measures that involve conceiving a child for these reasons. The medical team finds that the hospital’s policies do not address this topic. The medical team assigns hospital residents the task of researching the practice before proceeding.

In the United States, more than one hundred and seventeen thousand citizens are listed on the United Network for Organ Sharing’s (hereafter UNOS) list of persons waiting for life saving organ and tissue transplants (UNOS 2013, 12). Of those, thousands of these individuals are children who may not receive the organs they need to survive. In fact, eighteen people from the UNOS list die each day waiting for the necessary organs and tissues (UNOS 2013, 12). When effective medical treatments exist but the availability of those treatments is limited, what are parents and medical professionals to do? Some families in a similar position opt to have another child who will serve as a living donor for their ailing child. In this situation, the second child is labeled a “savior sibling.” Savior siblings can provide genetic materials either to a sibling or to another genetically compatible recipient in the family.

How are savior siblings created?

Category one, three, and four savior siblings are conceived naturally. Parents of category three and four savior siblings will have their pre-existing children tested for histocompatibility during the donor search. For parents trying to conceive of savior siblings after discovering the illness of a child, the probability of naturally conceiving a sibling who matches the genetic and immunological profile of an ailing child is approximately twenty-five percent and nineteen percent, respectively (Pennings et al. 2002, 534; Pennings 2004, 312). This means that a couple would have its fetus tested during pregnancy to ensure histocompatibility. If the resulting fetus fails to meet the necessary criteria, parents may choose to abort the pregnancy and try again or carry the child to term before trying again. Time constraints may render this plan ineffective, because conceiving and terminating pregnancies expends the limited time an ailing child may have remaining. But if parents have the time to carry an incompatible child to term before trying again to conceive a savior sibling, then trying to conceive a savior sibling naturally may not be worrisome.

Category two savior siblings are created with the assistance of reproductive technology. To create category two savior siblings, in vitro fertilization (IVF) is used to fertilize a human egg. Once the eggs are fertilized the attending specialist waits until the cells in the fertilized embryo divide into six or ten cells (Handyside 2010, 68). Then, physicians withdraw one or two cells from the embryo so that they can perform pre-implantation genetic diagnosis (PGD) and human leukocyte antigen (HLA) matching. PGD allows physicians to weed out embryos with genetic profiles that exhibit traits of severe disability or illness such as cystic fibrosis, Huntington's

disease, or other PGD-detectable genetic conditions deemed undesirable. HLA matching allows physicians to choose embryos that are genetically and immunologically compatible with an intended recipient; this increases the chances that the recipient's body will accept the new material post-transplant (Mayo Clinic 2011). The embryo exhibiting the most desirable traits would then be implanted into a woman to be carried to term.

For families seeking traditional savior siblings, using technology provides a more direct method than trying to conceive a histocompatible, non-afflicted child naturally (Sermon et al. 2004, 1638). The ability to conceive a child using technology would ensure that a family searching for a savior sibling might be able to reduce the number of trials necessary to achieve its desired aim. IVF, used in combination with PGD and HLA matching, was created for couples who needed to monitor the health of their fetuses after IVF and before implantation. The use of PGD allowed couples that had a genetic predisposition for life-threatening ailments to give birth to children who were free of a genetic malady that posed an imminent threat to the life of a future child (Handyside 2010, 72-74). Using PGD and HLA matching also increases probability of creating suitably matched donors for ailing children, whose families are unable to locate compatible registered or exiting related donors (Sparrow 2010, 668).

When do families use savior siblings?

There are no governmental agencies in the United States that have regulations or policies regarding the creation and use of savior siblings, but there

are professional organizations that suggest certain guidelines. The American Academy of Pediatrics (AAP), for instance, suggests that savior siblings should only be used when no willing adult donor exists – a last resort (AAP 2010, 396; AAP 2008, 456). Other factors that govern the discussion about the feasibility of creating and using savior siblings include “the patient’s age, comorbidity, disease and disease status, donor histocompatibility, and the time interval between diagnosis and transplant” (Samuel et al. 2008, 318). Each of these factors determines how the transplant recipient’s body could react to the introduction of new genetic material. Also, if the prospective recipient is too old, too sick, or has too little time, then a savior sibling may not be a viable solution. Moreover, some diseases or complications make the use of pre-existing siblings or adult donors infeasible. In those cases, created siblings are the better alternative to prevent further complications for the prospective transplant recipient (Samuel et al. 2008, 319).

How do other countries handle savior sibling creation and use?

United Kingdom

In the United Kingdom, discussions of both creation and use of created savior siblings resulted in a discrepancy between this proposed application of PGD and HLA matching and the Human Fertilization and Embryology Act (HFE Act) of 1990. When the Human Fertilization and Embryology Authority (HFE Authority) created the HFE Act of 1990, the Act made provisions for using embryo-screening technology to prevent a child from inheriting a disease that posed an imminent threat, like sickle cell anemia or Tay-Sachs disease, for example (Brownsword 2004).

In the early 2000s, several families appealed to the HFE Authority and asked the agency to allow the use of IVF with PGD and HLA matching to create children who could serve as donors for their ailing children (HFEA 2012). When families appealed to the HFE Authority on the grounds of helping their ailing children receive treatment, the HFE Authority denied the requests because it could not guarantee that any child born with the aid of this technology would not be harmed physically or scientifically. However, as a result of continued lobbying from parents, the Authority decided to monitor children born as a result of PGD typing from 2001 to 2004. Because the review process failed to yield any results indicating an increased susceptibility to illness or psychological harm that could be attributed to IVF and human tissue typing, the HFE Authority changed its policies to allow licensing for PGD and HLA matching for children created to serve as category two savior siblings. In July 2004, the HFE Authority issued a statement explaining that it had expanded its tissue typing policy to allow parents with severely ill children to create category two savior siblings (HFEA 2004).

In order to qualify for category two savior sibling creation, parents have to work with their child's medical team to prove that they have searched every available database for potential donors and found no match. To further protect category two savior siblings and their families, the HFE Authority began to require families to obtain two licenses before creating category two savior siblings (HFEA 2010). The first license granted the family the ability to create a savior sibling embryo – including IVF treatment, PGD testing, and HLA matching. Without the first license to perform testing, parents looking to create savior siblings would only be

left with the option of conceiving naturally. The parents would have to hope that the resulting savior siblings were adequate genetic and immunological matches, but even so a second license would still have to be sought. The second license, necessary for both created and pre-existing savior siblings, obtained from the Human Tissue Authority (HTA), grants the family the ability to harvest the necessary genetic material from its savior sibling and to implant the aforementioned material into their ailing child. According to the HFE Authority's savior sibling informational website, the Authority has granted licenses for savior sibling creation for ten ailments, but could expand the licensing program to include other licensed PGD conditions. There are more than one hundred conditions that PGD can be used to circumvent, but not all of these ailments necessitate the creation or use of a savior sibling.

This licensing process and the national payment scheme for health services have a lot to do with the UK's ability to regulate how the technology is used. One of the first families who participated in the procedure was the Matthews family of King's Lynn, Norfolk (Ellis 2010). Their daughter, Megan, suffered from Fanconi anemia and was given four years to live. No one in the family matched Megan well enough to serve as a donor. The family applied to the United Kingdom's National Health Service (NHS) for funding of the savior sibling procedure, which was granted. The parents applauded the NHS for their coverage of their daughter's treatment. Though the HFE Authority governs how IVF with PGD and HLA are used in medical facilities, the NHS, as the national insurer decides whether the costs of the procedure can be paid for by the national healthcare scheme. Families can still use

the technology even if the NHS refuses to pay, but the families will have to pay treatment costs out-of-pocket and must still obtain both sets of licenses.

France

France regulates the creation of category two savior siblings in a fashion similar to the British HFEA. Specifically, in 2004, French law began to allow parents to conceive children using IVF and PGD provided that both parents carried a genetic trait that could threaten the well being of the resulting child without interventions (Madanamoothoo 2011, 297). In 2006, supplemental laws allowed families with sick older children to create category two savior siblings to help provide genetic material for treatment. Since then, the French government has funneled over one million dollars annually into the research on the therapeutic advantages of category two savior sibling selection and creation (Chapoy 2011).

These research endeavors have been concentrated at a medical facility in Clamart. A Turkish couple entered Clamart, one of only three facilities in France that perform this kind of procedure, to create a category two savior sibling who could donate umbilical cord blood and stem cells. Their two pre-existing children are afflicted with beta-thalassemia, a blood disorder that interferes with hemoglobin production. The category two savior sibling, named Umut, born in April 2011, was healthy. His umbilical cord blood, rich with stem cells, was used to treat his two-year-old sister. The results of the transplant were not disclosed. However, the physicians in charge of the Umut's care, however, planned to wait a few months before they performed a bone marrow aspiration to collect material for Umut's four-

year-old brother's transplant. What could it be like for this child to know that he has served as a category two savior sibling for two siblings rather than one? This question will be discussed in Chapter 2.

On the other hand, some countries like Germany, India, and New Zealand, for example, prohibit the creation of category two savior siblings altogether (Dickens 2005, 93; 5W Infographic 2004, 82; Damiano 2011, 850). But as more parents are looking to explore savior sibling creation, testing, and use, more countries will have to decide to take a stance on this treatment option. As countries decide whether to erect or remove barriers preventing savior sibling creation and use, the imperative to analyze the possible risks of widespread acceptance of the practice grows.

How are savior siblings used?

Savior siblings can be used as living donors for a variety of procedures that include umbilical cord blood donation, hematopoietic stem cell (HSC) donation, bone marrow (BM) donation, and organ donation. Reported cases of created savior siblings have involved umbilical cord blood donation, HSC donation, and BM donation. In the United States, there are no known cases of created savior siblings being used as organ donors, but pre-existing savior siblings have been used. It is notable that the pre-existing savior siblings who have donated organs are mentally incompetent, so that these donations require only their parents' consent if the procedure is seen to be in the donor's best interest (*Strunk v. Strunk* 1969; *Hart v. Brown* 1972). Some bioethicists argue that created savior siblings should never be used for solid organ donation, but others point out that an argument could be made

to support the idea that a created sibling's best interests lie with donating an organ (Pennings 2004, 314).

This consideration of the best interests of the prospective donor stems from the legal cases involving some of the first donations made by pre-existing siblings: *Strunk v. Strunk* (1969) and *Hart v. Brown* (1972). The first case, *Strunk v. Strunk*, was decided in 1969 by the Kentucky Court of Appeals. The proceedings concerned a mentally incompetent 27-year-old man, Jerry, whose parents wanted him to donate a kidney to his ailing 28-year-old brother (*Strunk v. Strunk* 1969). The appellees, Jerry's mother and family, explained that if he did not donate to his brother the brother could die, and that would cause Jerry distress. The family claimed that Jerry depended on his brother for emotional and psychological stability. The majority of the court agreed with the parents' reasoning. The court decided that the parents could remove Jerry's kidney because the transplant would mean the survival of Jerry's brother. Moreover, the kidney procurement procedure was common and not excessively risky. This meant that the benefit of Jerry's giving a kidney would be greater than the risks to him.

Hart v. Brown (1972) was another sibling-to-sibling transplant case in which two parents fought to ensure that they could have one daughter donate a kidney to her ailing twin sister. Initially the treating hospital refused because both children were so young and the hospital administration wanted to be certain that they were not violating patients' rights.

In both cases, the parents were able to win the ability to have one child provide material for another. While neither of these cases involved the technologies

used to create savior siblings – the true genetic match – these cases paved the way for parents to use their children as genetic helpers for other children. Because of the case law created by these situations and those like them, parents may harvest transplantable materials from a savior sibling in the United States.

When the donor child is physically old enough to make the required donation, physicians extract the necessary genetic materials. For the most part, the known cases of savior siblings involve taking stem cell-rich umbilical cord blood, HSCs from the circulating peripheral blood, and BM. Umbilical cords are removed from newly born children after birth; this poses little risk (Herbert 2007-2008, 349-350). HSC and BM donation are also common procedures. Deaths related to HSC donation are rare at 1 in 10,000 (AAP 2010, 394; Mayo Clinic 2011, *Risks*). Some of the common risks of one or both procedures include low back pain, bone pain, aching muscles, fatigue, nausea, and occasional bleeding problems. There may also be pain and additional risks of harm associated with catheterization, including air trapped in the chest and infection. Even though these adverse effects are unpleasant, the symptoms can be managed with medications, making HSC and BM donation minimal risk procedures.

As for created savior siblings, the first category one savior sibling case occurred in 1991 when Mary and Abe Ayala gave birth to a second child, Marissa, so that they could have a bone marrow match for their teenage daughter, Anissa. Their eldest daughter was diagnosed with leukemia at the age of sixteen and needed a transplant. None of her family members matched her blood type. So, the Ayalas worked with physicians to conceive another child who could give their daughter the

life-saving donation that she needed (Ayala and Ayala 2011). Once Marissa was born, Anissa's medical team used Marissa's umbilical cord blood to create transplantable material that could save Anissa's life. After the transplant, ethicists and members of the public criticized the family for the use of one child to save another. Some of these critics also complained that a child as young as Marissa would not have had the opportunity to give her informed consent for the procedure. The family, on the other hand, pointed out that they would not have had to have another child if there were more marrow donors registered. They first searched through their extended family for matches. Then they asked their friends to be tested. When these options failed to yield suitable matches, they turned to strangers, who also could not provide the assistance Anissa needed. Besides allowing their child to die, what other option did they have?

The first reported case of IVF with PGD and HLA matching being employed for category two savior sibling creation resulted in the birth of Adam Nash, born in 2000, whose older sister Molly suffered from Fanconi anemia (Vacco 2005, 1181). After his birth, Molly's physicians extracted stem cells from Adam's umbilical cord to transplant into Molly. Though the medical professionals involved in creating Adam were unsure that the treatment would work, their hypothesis was confirmed when one year after her treatment Molly's illness had failed to return. Some critics described the Nashes as creating a "spare parts baby" and questioned their commitment to their son's health. Lisa Nash, the mother of the two children responded by stating that she and her husband "wanted a healthy child and it doesn't hurt him to save his sister's life" (CBSNews 2009).

Are there any additional risks associated with using savior siblings?

Even though families use IVF with PGD and HLA matching and human tissue typing to create category two savior siblings, the technologies are not infallible.

Donnatella Zammit was born in the United Kingdom in 2008 for the purpose of serving as a savior sibling for her brother (Weathers 2008). Her parents used IVF to conceive her and PGD and HLA matching to ensure that she could serve as a donor for her brother, Jamie – or so they thought. After birth, physicians realized that she did not match Jamie’s HLA profile well enough to provide him with bone marrow that could be used to combat his Fanconi anemia. Donna Zammit, the mother of the children, felt guilty about the situation because she had raised her son’s hopes by assuring him that the technology would produce a viable savior sibling. Donna explained that her son had become increasingly angry when several blood transfusions and searches to locate bone marrow donors proved futile. Creating a category two savior sibling seemed to be the final option for the family to save their son’s life. Donna and her husband told their son that the couple planned to have another child who could save his life (Weathers 2008). This news lifted his spirits and made him happier than his parents had seen him in a long time. Even when using the technology properly and doing everything right, IVF with PGD and HLA testing can still result in unforeseen situations. As such, it would be important to remind parents that IVF with PGD and HLA cannot guarantee a perfect match.

Equally interesting, Hank Greely alluded to another concern involving IVF with PGD and savior siblings in his lecture delivered at Wake Forest University on

28 March 2013. Greely explained that the earliest usage of IVF technology occurred in 1978 and resulted in the birth of Louise Brown, the oldest person created with this technology. She is only thirty-four years old. This means that physicians and researchers are still collecting information about the long-term effects that IVF and PGD technology may have on an embryo and the resulting child.

This information is troubling because in the quest to save lives, physicians and scientists have been relying upon information gleaned from apparent successes. The reality of the matter is that these same scientists and physicians cannot be sure that IVF babies or any of their tissues can last as long as the child resulting from natural conception. For all these physicians know, they could be exposing ailing children to risks unique to category two savior sibling tissue anomalies (Klitzman et al. 2013, 143). Should an ailing child contract a disease resulting from receiving their savior sibling's tissue, the savior sibling may have to face the psychological pain of his or her genetic materials causing another illness in their ailing sibling. The HFE Authority, when asked to comment on whether IVF posed an additional health risk to the resulting children, stated that some research had been completed, but that that research yielded no conclusive evidence (HFEA 2002).

Another risk that may arise is the psychological distress caused to the recipient child if he or she feels bound to the sibling who provided life-saving material. Psychological harm to the recipient child may also result if the donor child contracts as an ailment or dies as a result of providing the sibling with genetic material (AAP 2008, 456).

Conclusion

Parents decide to have children for many reasons: one of these reasons is savior sibling creation. Though legal, social, and physical concerns can influence a family's choice to pursue the use of this option, these are not the only concerns that should factor into the decision to use or not use savior siblings. In the next chapter, this thesis discusses the psychosocial effects that may result from serving as a savior sibling. This information will be crucial in understanding how participation in the savior sibling process can be beneficial or detrimental to the savior sibling.

CHAPTER 2 – PSYCHOSOCIAL IMPACT OF INTERSIBLING DONATION

During the informational briefing about savior siblings, one of the attending physicians asks about the psychosocial impact that serving this kind of purpose may have on the resulting child. The residents share this new information with the medical team.

The concept of savior siblings is a relatively new scientific phenomenon. As a result, there are very few studies that concentrate on savior siblings – created or pre-existing. While there are a few studies that involve psychosocial evaluations of sibling donors, not all of these studies fit within the scope of this thesis. Studies eliminated from this thesis include investigations that mixed data from pediatric donors with that of adult donors, investigations that surveyed only adult donors, investigations that based their conclusions on survey data obtained from parents, and investigations that performed surveys immediately after donation but did not follow-up with pediatric donors later on for data comparison. In discussions regarding the service of pediatric donors as savior siblings, it is most useful to use data derived from pediatric donors themselves. The two studies that remain are psychosocial studies by Wendy Packman and Kendra MacLeod (Packman et al. 2004; MacLeod et al. 2003). While both of these studies present information regarding pre-existing savior siblings, this data can provide some basis for thinking about the psychosocial effects of serving as a created savior sibling. Because there

are no studies concerning created savior siblings, anecdotal information obtained from public interviews by some of these children is provided.

How does knowing one's status as a savior sibling affect a child?

Jamie Whitaker, now seven, was conceived in the United States and born in 2002 in the United Kingdom because his older brother, Charlie, needed a stem cell and bone marrow transplant to help combat his Diamond–Blackfan anemia (DBA) (Levin 2011). When asked about his feelings about the reasons he was conceived, he replied,

I am happy I [donated genetic material to my brother] but I don't really feel like a superhero. I think I feel both good and bad about it but more good than bad...I know I was born [to save my brother] instead of being just born for me...it makes me feel close to Charlie...I also know Mummy and Daddy want me and love me and always wanted a big family.

In this particular case, it seems that Jamie's participation as a savior sibling served him well. His being born helped to supply the genetic material necessary to save his brother. Not only that, but post-transplant, his statements seem to confirm that he has found a niche in his family.

What about Marissa Ayala? If ever there were a poster child for savior sibling creation and use, Marissa would be it. The twenty-three-year-old young woman graduated from California State University Long Beach in May 2013 and is working toward becoming a speech pathologist (Ayala 2013). Marissa explained, in a 2011 interview with NBC News, that she never questioned the reasons why she was born,

but that anyone outside the family who did question the motives behind her birth was not putting themselves in her family's situation. She saw the relationship between herself and her sister as one of mutualism where neither would currently exist without the other, and that the women are just normal sisters.

If Jamie Whitaker and Marissa Ayala represented the majority of the stories of savior siblings, then perhaps the idea of savior sibling creation and use may not be all that worrisome. Unfortunately, there is another side of the collective savior sibling narrative. Being used as a savior sibling can negatively affect a child as well.

How does being used as living donors affect savior siblings?

In 2004, Wendy Packman and her team wanted to understand how hematopoietic stem cell transplants affected the psychosocial state of the transplant recipient's siblings. The researchers used non-donor siblings as a baseline for comparison. The study included 44 subjects: 21 donor siblings (pre-existing savior siblings) and 23 non-donor siblings. The subjects' ages ranged from six to eighteen at the time of interview. Packman et al. found that approximately one-third of all siblings affected by the sibling donor process – both donors and non-donors – were afflicted with moderate to severe post-traumatic stress disorder (PTSD) (Packman et al. 2004, 234). However, on average the savior siblings in this study had lower self-esteem than their non-donor counterparts. These savior siblings were also more likely to have low resolution scores on the Measures of Psychosocial Development (MPD), a personality development test with data self-reported by the test taker. This low score means that savior siblings surveyed were more likely to

experience feelings of “profound mistrust, doubt, a sense of vulnerability, guilt, inferiority, and identity confusion” (Packman et al. 2004, 244).

Furthermore, after donating, many of these savior siblings felt violated because they had been subjected to an invasive procedure that had the potential to do them harm. To some of these participants, the ability to save their ailing sibling’s life did not offset the distress caused by losing control over their own bodies. Many were told that their behavior was heroic, but none exploited the potential benefits of their hero status nor did they derive pleasure from participation. Instead, many of them had low self-esteem that appeared to be tied to the fact that after providing their genetic material, they were one of two focal points in the family. But, after the savior sibling recovered from donation procedure, he or she ceased to be a center of attention and joined his or her non-savior sibling counterparts in being secondary to the ailing sibling. As for the final facet of the study, art therapists recruited to help in the study asked savior siblings to draw pictures of their families. One child did not include herself in the drawing. Another child drew images that reflected animosity he had toward his ailing sibling. In discussions with the children, the researchers found that these savior siblings felt isolated or excluded from their families.

The researchers asserted that savior sibling distress and esteem problems stemmed from feelings that the donor children had no choice but to donate genetic material to their ailing siblings (Packman et al. 2004, 244-254). Some savior siblings were told that they would give their bone marrow to their siblings, whether they wanted to or not. Some pre-existing savior siblings were even provided with information about the procedure they were about to undergo, but the information

presented was beyond their understanding. In the end, the children simply nodded yes and agreed to the donation procedures because their parents wanted them to do so.

Returning to the Umut case, discussed in Chapter 1, of the first savior sibling born in France, the idea that this child was brought into the world to assist two siblings is even more disturbing. When transplants occur, there is no guarantee that the procedure will work. This means that a savior sibling may have to donate more bone marrow and stem cells later on. For Umut, his body has had to be invaded at least twice to harvest bone marrow to ease his siblings' suffering. The Packman study does not delve into whether repeated harvesting from a single savior sibling exacerbates lack of resolution of personality development issues or makes a child more susceptible to PTSD, though it does seem unlikely that harvesting multiple times for a single savior sibling would make a child feel better.

If the procedures work and Umut decides to take advantage of his hero-savior status, the process might help him find value in his existence. He would be the family member needed by all other family members – the hero. He could say, “I saved your life” or “I saved my siblings’ lives. Be nice to me.” He could extort presents, treats, time, or affection from his parents. But even if he did that, would having extra attention lavished on him help resolve any developmental issues that he may have in future or prevent him from addressing the issues? Every additional person a savior sibling must assist adds to the pressure to provide viable genetic materials. If the bone marrow Umut provides fails to help both siblings or only helps one sibling and causes complications for the other, and he is aware that his bone

marrow failed to provide assistance, then his body would have been invaded and he could feel responsible for the failure to rescue his sibling.

What are some of the long-term effects of being a donor?

Kendra MacLeod, Stan Whitsett, Eric Mash, and Wendy Pelletier, from the University of Calgary, performed a study of the psychosocial effects of donating HSC, BM, or both types of material to a sibling. The study surveyed fifteen pre-existing savior siblings between the ages of six and twenty at the time of harvesting. For the individuals surveyed in this study, all were aware of their status as pre-existing savior siblings at the time of the procedure.

In the initial stage of research, MacLeod et al. found two studies about sibling donors who provided material for HSC transplants where the ailing child survived – successful procedures. The research team, however, believed that more information could be gleaned from examining psychosocial effects of both successful and unsuccessful procedures. From their preliminary research, MacLeod’s group determined that the pre-existing savior siblings who participated in this study fell into one of two groups. The first group encompassed pre-existing savior siblings who felt animosity toward their ailing sibling, or were angry or envious of the attention received by their ailing sibling. The second group encompassed pre-existing savior siblings who were seen as being well adjusted, self-reliant, and close to their families.

The MacLeod study was created to elicit qualitative answers to the researchers’ questions regarding the donation process. The researchers asked about

the pre-existing savior siblings' relations to their families before and after providing donations, how their feelings toward their ailing sibling changed during the donation process, if they felt well informed about the risks of their procedures, and if they believed they could choose not to participate in the donation process (MacLeod et al. 2003, 225-226). The MacLeod study found that almost all of the study's participants felt that they had no choice but to donate to their sibling. Some pre-existing savior siblings were coerced or bribed by their family. Other respondents donated because they felt that it was their duty to provide the genetic material for their ailing siblings' treatment if it could save the siblings' lives. Some pre-existing savior siblings were even told that they were performing an admirable, heroic, mitzvah-like act. In other words, the pre-existing savior siblings provided assistance, lest they be seen as less than heroic or disloyal family members.

As for those who donated material to siblings in unsuccessful transplantations, many of the pre-existing savior siblings reported a sense of guilt and blame because their contribution failed to make a meaningful difference in their ailing sibling's prognosis. Because these pre-existing savior siblings knew that they were their ailing sibling's last chance and because these savior siblings failed to receive proper explanations of the science behind the transplant's lack of success, the guilt grew and festered over time. The research team also asked about the relationships between the donor and recipient, the success of the procedure, and how donating may have altered the donor's self image after the transplantation. Most pre-existing savior siblings reported that they were happy to have donated. Some pre-existing savior siblings who were below the age of majority at the time of

their donation were unconcerned about the thought that they may not have been asked for their complete informed consent because the health of their loved one was far more important to them.

There are, however, limitations to the MacLeod group's study. The setup involved eliminating some pre-existing savior siblings: those who were under the age of six at the time of donation because they may not have been able to adequately discuss their donation experiences and those whose interviews could have been seen as painful or intrusive. Though these exclusionary criteria were created to protect very young donors, their exclusion from the survey may have also prevented the collection of important data. Some of these very young donors may provide information that could provide a basis for comparison for the psychosocial effects of created children. Some of these very young children may not have been old enough to remember donating genetic materials. As such, studying their psychosocial experiences could provide information about the best ways to inform future savior siblings about the reasoning behind their use as saviors. These children need not be interviewed when they are still very young, but they could be contacted when they are old enough and comfortable enough to speak about their experiences.

Another limitation of the study concerns surveying savior siblings at one time between two and fifteen years after the donation procedures. A more comprehensive study may include more participants as well as divide data in such a way that that researchers can examine how age at the time of donation and time since donation can affect a savior sibling's experience. Both types of information would provide a richer level of understanding of the savior sibling's predicament.

Conclusion drawn from the psychosocial study of pre-existing savior siblings

In both the Packman and the MacLeod studies, children used as savior siblings experienced anxiety and stress because of their participation. Many felt like they were not informed about what would happen to them and did not feel like they could back out of their predicament. As a result, the majority of these pre-existing savior siblings felt that they had no control over their own bodies. Again, these participants were pre-existing siblings, which means that the data may not be completely translatable to created savior siblings. What is clear is that because the predicament of **category** three and four siblings is somewhat analogous to that of **category** one and two siblings, the stresses experienced by the former group will be felt either in whole or in part by the latter group. If one were to speculate, one could hypothesize that the experiences of created savior siblings may even be worse than those experienced by pre-existing savior siblings. Because we have this knowledge, if we must use a savior sibling for any reason, we must do so very carefully and sparingly. Even so, reduction of psychological, mental, physical, and developmental stress should be a major focus going forward.

CHAPTER 3 – THE ETHICS OF SAVIOR SIBLING CREATION AND USE

After listening to the informational and psychosocial briefings, the medical team assembles a list of possible concerns that may be relevant for the Mason case and any future cases of this nature.

In this chapter, I discuss the ethical issues involved with savior siblings. For this ethical analysis, I draw on the ethical framework devised by Bernard Gert, Charles M. Culver, and K. Danner Clouser (hereinafter GCC). The GCC framework includes moral rules that are derived from studying other codes of ethics and distilling all of these codes down to their common elements. Rather than seeking to promote the most good, a concept that is difficult to precisely define, the framework focuses on minimizing harms. The moral rules encompassed in this framework include *do not kill, do not cause pain, do not disable, do not deprive of freedom, do not deprive of pleasure, do not deceive, keep your promise, do not cheat, obey the law, and do your duty* (Gert et al. 1997, 34).

As explained by GCC, the violation of the first five rules generally lead to harm while the violation of the next five rules may lead to harm. These rules create a lens through which discrete events may be examined for their harm-causing potential. Because of the way these rules have been devised, they can be combined to form hybrid rules (e.g. a young man who decides not to drink and drive because someone could be harmed by his actions draws upon *obey the law* and *do not cause*

pain). Each rule can also be weighted differently based upon the gravity of the moral question being asked. For example, a physician may amputate the limbs of patient suffering from severe frost bite, violating the rules of do not disable – the patient will lose the use of his or her limbs - and do not cause pain – the patient will be in psychological and physical pain following amputation. While this may be true, failing to amputate the damaged limb would lead to the death of the patient, violating the rule do not kill. Not treating the patient would constitute doing harm because it would result in the death of the patient. To assist the patient in refusing the amputation, the physician could provide pain-relieving medication. To mitigate the disabling affects of amputation, the physician could refer the patient to a prosthetic specialist and physical therapist. Even though amputation may violate two rules, violation of the rule that prohibits killing carries more weight. Therefore, the decision to amputate is the better of the two options because the patient will still be alive and has the ability to regain mobility.

Finally, though these rules have phrases in them like “do not...” or “do...” this does not mean that one should never commit a certain act or that one should always perform another kind of action. Rather, what these phrases mean is that if one has the opportunity to avoid a “do not...” activity, one should. But if one must violate a rule, it must be because following another rule is far more important or because the expected outcome of violating a rule provides greater long-term benefit.

Additionally, each moral rule has its own nuanced meaning within the context devised by GCC. For instance, *do not kill* means that an agent should not pursue an action that will result in death, although this does not strictly mean that

an individual should refrain only from actions that lead to death. In fact, this rule also means that one should not undertake actions that may lead to irreversible loss of consciousness. The rule *do not cause pain* encompasses the causing of physical pain as well as emotional and psychological pain, and anxiety. *Do not disable* comprises not undertaking actions which may mentally or physical impair another individual or retard someone's ability to make choices for him or herself. *Do not deprive of freedom* refers to the idea that one individual should not act in a way that results in another person's being unable to perform an activity of his or her choosing. For instance, a physician may not enroll a patient in a study without the patient's consent.

Next, the rule *do not deprive of pleasure* implies that one should not take something good from another individual or prevent the individual from obtaining something good, either in the present or in the future. *Do not deceive* means that one should not lie or withhold information from another individual. The rule *keep your promise* signifies that one should always honor his or her commitments. *Do not cheat* implies that one should follow the rules unique to each situation. The rule *obey the law* means that if laws exist to govern certain types of behavior, then one should follow them. Finally, the rule *do your duty* includes fulfilling one's responsibilities to society. GCC make clear that this is not the universal concept of one's duty, but rather a duty one may have to a specific community or group of individuals. Altogether, this framework represents a body of evaluative criteria that may be used to pick apart different situations in order to analyze the savior sibling scenario. With the assistance of GCC, some of the positive and detrimental aspects of

creating and using savior siblings will be analyzed to bring to highlight relevant concerns.

Why use the GCC framework?

While the GCC ethical framework was first published in the mid-1990s, it is not a common means of working through ethical dilemmas. In fact, many scholars rely on the works of Beauchamp and Childress (hereinafter B+C) or Kant, or frameworks like casuistry, consequentialism, or utilitarianism. This thesis, however, does not use these evaluative methods, though the GCC framework may overlap with each of these theories. The GCC framework has many advantages over the B+C ethical framework. The main justification for using this framework over others is that the GCC framework has many more rules, which can be customized and weighted depending on the situation being analyzed and the beliefs of the person using the framework.

The B+C framework, however, has four rules that can be misused as a check-box method. That is to say that the B+C method requires the users to look for *beneficence, nonmaleficence, justice, and respect for autonomy (of the decision-maker)* (Beauchamp and Childress 2009). If the user can find evidence of these principles in the scenario in question, then a case can be made that the practice he wishes to perform is ethical. The issue with following this framework is that it has the ability to lull the user into a comfort zone where recommendations can be made quickly. While fast decision-making is a great goal to strive for, that goal is not always in line with thorough analysis. The GCC method, conversely, cannot so easily be carelessly

used. This method forces its users to – borrowing a term from the visual arts discipline – make *the familiar strange*. In other words, users must mull over several aspects of a proposed action, picking it apart to understand the prospective consequences of the decision. As a result the framework first asks users to examine the deficiencies in any decision so that those deficiencies may be ameliorated. Then, if the decision has the potential to harm another, the framework asks the users to look for the benefit a decision may provide in spite of violating a moral rule. The framework is designed in this way because the user, if he or she is behaving rationally, should be acting in a way that promotes good for someone.

As for the other ethical frameworks like utilitarianism and deontology, these frameworks are not separate from the GCC framework. The utilitarian framework seeks to maximize the good by increasing utility and minimizing harm. The problem is when we ask the question, “*The good according to whom?*” It is difficult for an individual to describe an action that could be performed that all persons would see as good. It is also difficult to say that one action leads to greater good than another. Harms as explained by GCC have the ability to undermine socially acceptable values and can lead to suffering for many. However, there are degrees of suffering, and some of these levels of suffering are acceptable (e.g. requiring children to receive vaccinations before attending a public school violates the rules of *do not disable*, *do not deprive of freedom*, and *do not cause pain* but the benefit is the prevention of the spread of life-threatening diseases). The element that makes GCC an ideal framework for examining savior siblings is the idea that all conclusions must be justified in some way.

What considerations should factor into the decision to create a savior sibling?

Created savior siblings are in an interesting predicament because they are born with the purpose of providing genetic material to ailing siblings. Examining savior sibling creation, whether it is through natural or technology-assisted means, is a somewhat complex issue. The rules *do not kill* and *do not cause pain* may be intertwined for savior siblings. While the selected savior sibling is not killed during the process of savior sibling creation, other prospective savior siblings may be. Some parents may choose to create category one savior siblings. The families may conceive several healthy fetuses that do not fit the ailing child's genetic or immunological profile. Some of these healthy fetuses may be aborted so that the parents may attempt to conceive a match. Likewise, families looking to use IVF with PGD and HLA matching may choose one fertilized embryo from a large selection and dispose of the remaining fertilized embryos. If the parents of the savior sibling choose to tell the child that many prospective savior siblings were not born so that this child could survive, this may cause psychosocial pain to the child. This psychological pain could be dealt with by being delicate in telling the child, if that is even necessary, but the child could also participate in counseling or therapy. Otherwise, even though the savior sibling will not be killed directly, he or she might feel pain or guilt that so many prospective lives did not have the chance to be born.

The other way to look at the rules *do not kill* and *do not cause pain* would be to say that category one savior sibling creation causes pain because it may lead to the abortion of fetuses that do not match the transplantation needs of the ailing

child. Conversely, category two savior siblings are born after the embryo that is the best match is selected and implanted. By using IVF with PGD and HLA matching, the parents worked to ensure that any resulting child who was born did not have the same ailment that plagued his or her sibling. Even if one disagreed with the disposal of unused embryos, which those who believe that embryos are persons could see as killing, this disposal could be justified by the birth of a healthy child.

As far as the other GCC rules are concerned, creating the actual savior sibling, as distinguished from using the savior sibling, does not lead to the violation of the rules of *do not disable, do your duty, do not deprive of freedom, do not deprive of pleasure, do not deceive, keep your promise, do not cheat, and obey the law*. It is a parent's duty to protect children from pain and harm. In that way, using IVF with PGD and HLA matching to prevent a child from being born with a painful life-threatening disease is helpful to the prospective savior sibling. Moreover, using technological interventions to ensure the health of a future child also assists parents in preventing the disablement and lack of freedom that a savior may experience without it. When it comes to obeying the law, there may be laws that govern when a fetus can be aborted. So long as the parents observe these laws, this does not directly harm the savior sibling. As for the other rules regarding pleasure, deception, cheating, and promise keeping, during the creation stage the savior sibling would not exist in a state where these rules could be violated against him or her, yet. In other words, IVF with PGD and HLA matching is analogous to using IVF for other procreative measures requiring technological intervention.

What considerations factor into the decision to use a savior sibling?

When examining the use of savior siblings, the rules *do not kill* and *obey the law* are closely intertwined. The fear that some critics of the savior sibling process have is that savior siblings will become living spare parts reservoirs for their ailing siblings, used until the child dies (Mills 2005, 2; Devolder 2005, 583). This way of thinking is in line with the slippery slope argument that will be addressed in the next chapter. Some may even suspect that parents will show preferential treatment to ailing children and sacrifice the well being of the savior siblings. The idea that a physician would intentionally participate in an act that would result in the harming of a child would lead to loss of professional licenses and criminal charges ranging from assault to murder. The legal and professional climate in the United States would not allow this kind of unethical behavior.

In regard to the rule *do not cause pain*, one must consider what kinds of procedures a savior sibling will be exposed to, if a less painful alternative is available, and how often the savior sibling must provide material. Procedures that savior siblings have been involved in exist on a spectrum ranging from umbilical cord blood donations to HSC donations to BM donations to solid organ donations. While the three former procedures are common for both pre-existing and created savior siblings, the latter procedure has only been used with pre-existing savior siblings. Umbilical cords of every child are removed after birth. A new study from the Cochrane Collaboration asserts that leaving the umbilical cord attached up to ten minutes after birth can decrease the chances of the child's developing anemia later during infancy, but removing the cord early would not cause pain (McDonald et

al. 2013, 15). If anything, the procedure provides no benefit to the child from whom the umbilical cord and its stem-cell rich blood are taken. As for HSC and BM donation, the pains associated with these types of donations are related to the way in which the material is recovered. Bone marrow aspiration, for instance, involves withdrawing bone marrow directly from the hip. This results in pain in the hips and back, nausea, vomiting, and bleeding problems. Conversely, apheresis, which involves the insertion of catheters into the veins of the donor, includes the pain of growth factor injections that are used to increase the number of hematopoietic stem cells in the blood. Savior sibling solid organ donation, though rare, involves the most physical pain derived from cutting into the body, complications from organ recovery, and healing time.

As far as repetition of donation is concerned, suppose a savior sibling was born to provide BM for a sibling suffering from leukemia. The ailing child has had his or her BM ablated in preparation for a transplant. The medical team has recovered HSCs and BM from the savior sibling and implanted the genetic material into the ailing child. The ailing child's condition improves and he or she appears to be cured months after treatment. Three years later, the ailing child's cancer returns. The medical team may decide to use the savior sibling again, and the savior sibling will have to make donations beyond the initial provision of umbilical cord blood and tissues. In the film *My Sister's Keeper*, discussed later in Chapter 4, the main character, Anna, was born to serve as a savior sibling to save her sister from cancer. Because the sister's cancer returned multiple times, Anna underwent several medical procedures and was almost coerced into donating a kidney to her sister

against her will. While a case like Anna's has not been reported yet, Umut from France, who has donated bone marrow to two siblings represents the first step toward an Anna-like situation. Considering this scenario in conjunction with data provided by Packman and MacLeod regarding the psychosocial distress experienced by pre-existing savior siblings, it is possible that similar harms could be caused to created savior siblings, especially any future saviors used the way Umut has been. In short, recovering multiple donations from a savior sibling may increase the likelihood of these children developing PTSD and other self-esteem issues.

Next, consider the following: Suppose a child is conceived to provide a kidney for her older brother. Suppose this brother receives the kidney after the girl's birth but she suffers some life altering complication that renders her remaining kidney non-functioning due to a severe infection that causes the remaining kidney to fail. Now, the family and the medical team know that her blood and HLA matching type are rare so it is fair to assume that it will be difficult to locate a suitable donor. The child could be placed on dialysis indefinitely. However, that leaves the child susceptible to arteriovenous fistula failure – the access vein is no longer accessible – or postsurgical infection, though both of these complications can be resolved with surgery and medication (Briones 2010, 1732-38). The family could also wait until a viable donor organ becomes available. Would physicians recommend that the parents conceive a second savior sibling and submit said child to the donation process as well? In Chapter 1, this thesis explained that savior sibling creation and use were born out of a lack of available donors for pediatric patients. What would an affirmative answer to this question say about the current donor registry programs?

Finally, the rules *do not disable, do your duty, do not deprive of freedom, do not deprive of pleasure, do not deceive, keep your promise, and do not cheat* are more difficult to generalize during the use portion of the savior sibling process. This is because the violation of any of these rules depends on the age of the savior sibling at the time of donation, the discussion parents may have had with the savior sibling prior to the donation procedure, or willingness of the child to participate in the donation procedure. For instance, one set of parents may forcefully persuade an older child to donate bone marrow to a younger sibling. The parents may agree to give the prospective savior sibling a reward in return for participating in two bone marrow aspirations. If the parents force the savior sibling to participate in more than the two procedures and refuse to tender the reward, then they violate the rules *do not deceive, do not deprive of freedom, do not deprive of pleasure, and keep your promise*. Though these rules are difficult to discuss because of the different ways they can be combined to examine savior sibling usage within individual families, they can still be informative when applied to specific familial situations.

Conclusion

The GCC framework is a useful tool for examining savior sibling creation and use. With this framework, one can determine that creation of savior siblings does not cause direct harm to them; however, the use of these children may harm them. Also, this framework helps to highlight that some means of using savior siblings are less harmful than others. The next chapter highlights some dangers of unregulated savior sibling use.

CHAPTER 4 – THE PRESENTATION OF GENETIC SAVIORS IN THE ARTS

After the medical team considers some of its ethical obligations, a resident locates two films related to savior siblings. While the films have no medical bearing, the films offer information about how the procedure may be viewed by others in the public and in the medical world. They also believe that the films may stir additional thoughts in the staff that may stimulate new ideas about treatment methods. The team decides to view the films together.

Film writers occasionally use material from the news as topics to explore in film, savior siblings being one of these topics. Films are wonderful tools for analyzing bioethical issues because creative minds can create and explore complex issues without the high-stakes concerns of real life examples. Furthermore, creative representations of possible situations allow writers and film directors to craft multi-faceted characters with thoughts, feelings, emotions, and motivations that help to illuminate different ways of thinking about difficult problems. While it can be tempting to examine a practice and immediately rely on a gut-reaction to decide if it is right or wrong, giving an individual – real or imagined – a voice to explain his or her position forces physicians, bioethics scholars, and others to look more deeply when addressing an issue or question. In fact, the use of film and written fiction builds a social and emotional connection to characters with diverse views and opinions. In listening to these stories and narratives, a scholar must reason his or

her way through to an ethical path that acknowledges and respects several viewpoints. Furthermore, because many of the savior siblings that this thesis seeks to protect lack the power of language to speak for themselves, these fictional characters must speak for them until these savior siblings can do so on their own.

My Sister's Keeper, based on the novel by Jodi Picoult, and *Never Let Me Go*, based on the novel by Kazuo Ishiguro, are two motion pictures that introduce laypersons to the concept of savior siblings. In *My Sister's Keeper*, a young girl sues her parents for medical emancipation. The court proceedings reveal that the young girl actually chooses to pursue emancipation at the request of her ailing sibling (Cassavetes; Picoult 2005). While *My Sister's Keeper* presents a plausible present, *Never Let Me Go* examines a terrifying mirror of an alternate history spanning from the 1970s to the present (Romanek; Ishiguro 2010). *Never Let Me Go* focuses on the lives of three donor children who live through an unambitious youth, only to spend their early adulthood donating their organs to strangers until they make their final donation and die. Though the two works concentrate on children, the works differ in the way the film actors present the dynamics between the donor children and the adults surrounding them. In this chapter, the thesis explores some of the ethical implications of the behavior of the adults involved in both situations and discusses how the presentation of savior siblings in this way could affect how one views savior siblings.

Although *Never Let Me Go* and *My Sister's Keeper* are fictional, the issues raised by both stories illustrate the possible results of unrestricted savior sibling creation and use. This discussion asserts that if left unchallenged, the progression of

the usage of savior siblings may lead to the exploitation of children such that courts would have to intervene on behalf of the rights and the future health of the child. As such, I assert that constraints should be developed to prevent parents and caretakers from exploiting their wards by taking all the organs and tissues that they need and leaving the child to suffer the physical and psychological pain as well as any future health concerns.

The two films also differ in the presentation of the use of the children in each scenario. Anna, in Cassavetes's film, is a savior sibling donor while the children in Romanek's film are genetic donors. While both scenarios involve children providing genetic material to another individual, Anna is strictly a savior sibling in the sense that she is related to, lives with, and interacts with the recipient of her donation. Conversely, in Romanek's film, the genetic donors are individuals who cannot meet the person who receives their donations. Moreover, the genetic donor is created with the sole purpose of being used as a spare parts child. While the two beings serve a common function, each position has its own positive and negative aspects. Unfortunately for the genetic donors in Romanek's film, their genetic donor status comes with far more life-threatening detriments than positive attributes.

What can be learned from *My Sister's Keeper*?

The film *My Sister's Keeper* is set in a contemporary timeline and follows the story of an adolescent girl named Anna during the last few months of her older sister Kate's life. During the first scene of the film, Anna explains that she was born with one purpose: to save her sister Kate by serving as a savior sibling. Anna exists

because she provides genetic materials for her older sister, who has been battling cancer since toddlerhood. From birth, Anna spends a lot of time in the hospital because she spends so much time donating bone marrow and other tissues to Kate. Initially, the treatments given to her older sister help to send Kate's cancer into remission. But as the years go by, more donations are needed because Kate's cancer returns multiple times.

One day, Kate's kidneys begin shutting down. Her physician suggests that she have a kidney transplant, although the success of the transplant is uncertain. Even so, the girls' mother is adamant about trying whatever measures are necessary to save her daughter's life. This mother, so consumed with trying to fulfill her duty to protect Kate from her illness, is willing to subject Anna and Kate to whatever extreme measures are necessary for even the chance of keeping Kate alive. While this conviction is admirable, it is this conviction that is at the heart of the disintegration of the familial bonds. As a result, the two sisters conspire to sue for the younger girl's right to bodily integrity, so that she can keep her kidney. By the end of the film, Anna is forced to reveal that Kate wants Anna to have rights to her body because she is so tired of submitting her sister and herself to painful medical procedures and would prefer to die peacefully.

As previously mentioned, cases like *Strunk* and *Hart* made it possible for parents to obtain organs and other genetic materials from their children. The difference between either of these real life cases and that of Anna's family is that the savior siblings in *Strunk* and *Hart* were incompetent. Jerry Strunk could not speak for himself because of his disability and the Hart girls were only seven when their

cases went before the courts. Neither party had the ability to voice either assent or dissent to the removal of their kidneys. However, in Anna's case, she is an adolescent who has lived through the extraordinary ordeal of having genetic materials drawn from her body repeatedly. But the odd thing about the court case depicted in Picoult's work is that even though Anna does possess knowledge of her sister's case and the possible outcomes her actions could have, the testimony provided by the experts testifying in the case make it seem as if the court is wavering between kidney donation and an inability to decide altogether.

For savior siblings, this presentation of conflict is critical, because it affects the layperson's understanding of the savior sibling's predicament. Anna knows the risks of what she is doing and was initially willing to donate, but now no longer wishes to do so, which is her right. Although the Anna character is a product of fiction, the film highlights a real life vulnerability of the current savior sibling system, which makes no explicit provision for an independent advocate for the aforementioned savior sibling.

While Kate and Anna's mother fights valiantly to do her duty to preserve Kate's well being, her own daughters, both the savior sibling and the ailing child, must fight together to stop a process that is hurting them both. Anna's body was being used as a reservoir for healthy tissues and she had no one advocating for her until she sought to procure the services of a lawyer herself. If nothing else, with the number of procedures Anna had to undergo for Kate's sake, it is amazing that not one of the adults – those who had the greatest responsibility to protect this savior sibling – suggested that someone should serve as an advocate for Anna.

Even though there is no available evidence that a child has been used in this way in real life, there is no system in place to officially monitor the savior sibling creation process to prevent this from happening. If anything, the system currently in place in the United States relies on physicians and parents to use their best judgment in order to protect the savior sibling. Of course Child Protective Services or a judge could step in to arbitrate any disputes or to provide protection for an endangered savior sibling, but these parties are typically alerted during or after any alleged abuse rather than prophylactically involved.

In the UK, HFE Authority oversees the creation of savior siblings and the HTA oversees the usage of savior sibling tissues. Both organizations take steps to examine the welfare of these children to ensure that savior siblings are not being overused. The involvement of both of these agencies slows down the entire process and requires parents to provide evidence that they have searched for alternatives and proof that those alternatives have failed to yield acceptable results. As a result, there is an agency overseeing the entire savior sibling creation and use process so as to prevent abuse of savior siblings. Unfortunately, this component is missing in the United States.

Because there was no system available to assist Anna, she felt forced to sue for medical emancipation, which she eventually receives. Unfortunately, the gesture is wholly symbolic because Kate passes away before Anna receives notification. The idea that a savior sibling would have to sue his or her parents for rights to his or her own body seems extreme and may not address all of the savior sibling's psychosocial concerns. Moreover it would be expensive for every aggrieved savior

sibling to file a lawsuit. Instead, what can be gleaned from this film is that the process of creating and utilizing savior siblings may benefit from having an independent third party overseeing the donation process and advocating for the savior sibling.

What may be learned from *Never Let Me Go*?

The film *Never Let Me Go* is set in dystopian 1973 in a timeline where clones of existing individuals are created for the sole purpose of being used as organ and tissue donors for the people they are modeled after, referred to as *originals*. Even though these clones do not begin donating until they are over the age of eighteen, they cannot opt out of being used as disposable genetic donors. By using these children as organ donors, the originals can extend the average human lifespan beyond one hundred years. In their adolescent years, the genetic donors are housed in boarding schools – sequestered from the general human population – where they pursue artistic endeavors, play sports, and engage in sexual relationships (Romanek). While at school, the genetic donors spend their days checking for bruises and signs of disease, consuming massive quantities of vitamin and antibiotics, and avoiding addictive drugs and high-risk physical activities. All activities ensure that each genetic donor maintains proper physical health.

The film follows three adolescents, who live in a boarding school called Hailsham, from adolescence until death. Once the genetic donors reach the age of majority, they are moved into group housing where they wait to be called to make their first donations. The typical genetic donors makes anywhere between one and

four donations to his or her original before *completing* – dying after donation of a major organ.

Rather than being treated like human beings, these genetic donors are sacrificed, supposedly for the betterment of mankind. In reality humans will sometimes sacrifice some lives in exchange for others. For example, countries send soldiers all over the world to defend their country, first responders die in the process of saving civilians, and physicians die while treating patients with highly infectious fatal diseases. In almost all of these cases, those who put their lives in danger *volunteer* for their positions. These professionals understand the consequences of their service and have the opportunity to consider alternative social niches. The genetic donors of *Never Let Me Go* do not know that there are other ways of living their lives.

The physicians and school administrators of Ishiguro's world, however, assert that the expended genetic donors' lives will serve the human condition by extending the lives of those the donors are modeled after. Moreover, because this particular kind of therapy works and because human beings have become accustomed to using genetic donors, ceasing to offer this form of disease treatment would cause upset amongst the general human population. The donation process, however, should not merely serve to cure the ailing but should also serve to protect the health and welfare of the genetic donors. Any medical institution should acknowledge the sacrifice of these genetic donors, and entertain the possibility that a genetic donor may dissent from donation if only he or she were permitted to speak.

This is not to say that any hospital existing outside of fiction could or would allow repeated organ collection from genetic donors until said genetic donors passed away. It is merely to state that whenever the decision is made to draw genetic material from a child, protections should be in place to protect that genetic donor during the donation process. This film is supposed to foreshadow how the quest to prolong and sustain human life proves most costly. Not only has the fictitious government prioritized the placement of its citizens over these abject individuals; it openly accepts the practice of killing genetic donors on the operating table.

The genetic donors in the film are told that leaving the care of their schools and group homes would result in their deaths because the world is a harsh place. None of the genetic donors in the schools like Hailsham are provided with substantive education programs that could give them life skills. All of the donors' basic needs such as food, shelter, and travel expenses are provided without their having to work or to ask. Even if these donors had the desire to live, they have no ability to support themselves in a foreign world like that occupied by the originals. In other words, even though the donors could run away from their housing units, their belief in the dangers of the world of the originals and their lack of marketable skills translates to a lack of alternate possibilities. In this case, these individuals may not know that they even have a choice.

The dystopian world in the film *Never Let Me Go* presents a visual representation of the slippery slope argument stemming from savior sibling procedures. The use of cloned genetic donors started with the growth of

transplantable organs and bone marrow before progressing to the creation of entire human beings. The government justified the use of these children by classifying these individuals as property and methods of treatment rather than human beings. The outside community accepted the fate of these children, because they had convinced themselves that no other alternative existed. As viewers of this film, medial professionals, worried parents, and ethics committees are being challenged not to accept this reasoning as a good excuse to continue to use children. They are instead dared to seek alternatives before this excuse can be issued.

Conclusion

Creation of savior siblings should not be the first option for treating an ailing child's sickness. But if this method is the only solution left to a treatment team, then some type of protection and education program should be in place to advocate for the protection of the savior sibling. Savior siblings are human beings drafted into their parents' war against their sibling's ailment. With luck, their responsibility in that war should end after the donation of the necessary material using the least invasive procedure possible – umbilical cord blood, HSC, or BM donation. This is where a line should be drawn. Though the children in these films are fictional, their struggles and disappointments are reminders that the quest to save lives can go too far. In cases where savior siblings are to be used, some one should be present to advocate for the savior sibling and to act in that child's best interest as well as the ailing sibling's interests.

CHAPTER 5 – MANAGING SAVIOR SIBLING CREATION AND USE

The medical team, after reviewing as much information as possible, begins to formulate a resolution plan that will also provide guidance for future savior sibling cases that may enter the hospital. The staff consults the works of bioethicists and psychologists to use as guides for crafting hospital specific policies.

In previous chapters, this thesis discussed how creating and using savior siblings could affect these children. This thesis started by presenting the climate that led to the use of the first savior siblings. Then this thesis presented studies that discussed how serving as a savior sibling can adversely affect one's psychosocial health. Previous chapters also reviewed ethical considerations and popular media depictions relating to the creation and use of savior siblings. Now it is time to turn to means of collecting comprehensive savior sibling data and reducing harms caused to these children.

There are several steps necessary to help future savior siblings: (1) devising alternative programs that families may access to locate donor genetic materials and (2) drafting guidelines that parents and physicians should follow to protect the wellbeing of all savior siblings. Step One comes into play either before or during the discussion to create a savior sibling. This step includes two key pieces: (1) encouraging the standardization of using umbilical cord banking, and (2) encouraging standardized genetic testing of parents before procreation and possibly

standardizing the prophylactic use of IVF and PGD. Step Two entails developing a framework that allows medical professionals the opportunity to collect better data about savior siblings. As data pertaining to the psychosocial health of savior siblings becomes more robust, medical professionals can tailor their therapeutic approaches to address savior sibling related concerns while providing treatment for ailing siblings.

Why seek alternatives to savior sibling creation and use?

The options presented in this chapter provide the reader with other routes that could be pursued to relieve savior siblings of some of the large burden placed in their charge. In creating other options, we may be able to reduce the number of savior siblings being produced each year. That may provide researchers the time necessary to speak to the savior siblings currently in existence and to slowly create a system to address the grievances resulting from and the inadequacies of the current, unstructured savior sibling creation system. In order to hear any voices or to conduct any studies that can meaningfully affect the well being of savior siblings, one must first create an orderly way of collecting that data. Providing counseling and a donor advocate for a child allows a third party viewer to enter into health care discussions, but also allows quality data to be collected as it is discovered.

By participating and engaging with the steps listed below, savior siblings and their families put themselves in the position where they will be participating in an ongoing study for an indefinite amount of time. But is this not what a quality study would permit researchers to do? A savior sibling will legally be considered a child

until he or she turns eighteen. After that age, an individual is legally able to make decisions for her- or himself. In addition, in many instances, minor children who are sufficiently mature and knowledgeable are recognized as able to take part in health-related decisions. Thus, improvements and alterations to the guidelines governing savior sibling creation and use could be tracked thoroughly over time, with more than short sporadic forays into the lives of these children, both until they reach the age of eighteen and, with their permission, even into adulthood. The ability to track some savior siblings over the course of time may ultimately prove better and healthier for savior siblings in the future.

What savior sibling regulatory models can contribute to the way one thinks about savior sibling monitoring?

Between 1987 and 2000, sixty minors in the United States, some as young as ten years of age, donated kidneys (Delmonico 2002, 333-336). Sixty percent of the recipients were adults and forty percent were children. Even though the American Academy of Pediatrics (AAP) agrees that minors may provide donations, donations can only be made under stringent circumstances. The AAP's guidelines comprise five conditions, four of which originate from the Live Organ Donor Census Group's guidelines: "donor and recipient highly likely to benefit, surgical risk for the donor is extremely low, all other deceased and living donor options have been exhausted, the minor freely assents to donate without coercion (established by an independent advocacy team), emotional and psychological risks to the donor are minimized" (Abecassis 2000, 2919-2926; AAP 2008, 457). The AAP, in drafting its guidelines,

sought not only to create a system that could study the full range of influences that serving as a savior sibling can have on a child, but also to minimize the number of court proceedings needed to decide whether a minor could serve as a donor. What is interesting about these guidelines is that they imply that young children and children with special needs that impede their ability to communicate should not be used as donors. Furthermore, these guidelines cause the adults surrounding the prospective donor to consider the effects that the donation process may have on the savior sibling and try to minimize the impact.

Philosopher Guido Pennings and his colleagues also developed a set of guidelines for parents to follow when seeking to create savior siblings (2004, 311-317). One of the benchmarks included in these guidelines concerns a parental counseling component. This component is used to ensure that parents understand that the savior sibling's donation may not make a difference in the ailing child's prognosis. Counseling could also be used to determine the parents' intentions for the savior sibling and to discuss the risks of genetic material donation for both the savior sibling and the ailing sibling. This component is important because it reinforces that having a donor and performing a transplant only provide the hope of a cure rather than a guarantee.

Lastly, bioethicists Susan Wolf, Jeffrey Khan, and John Wagner's savior sibling guidelines include two provisions that this author finds intriguing (2003, 335). The first is that the donor child should be assigned a doctor and that any harvesting procedure should involve the parents and an ethics body providing permission. Assigning the savior sibling a physician ensures that both children have a medical

advocate working for each individual's health instead of maintaining a purely big picture view of the issue. Also, while requiring both parental and ethical review for certain procedures is an interesting idea, the bioethicists would prefer judicial review of cases in jurisdictions where no laws about created or pre-existing savior siblings exists. It would be interesting to see how this would work, because situations requiring savior siblings involve complicated diseases, complicated familial relationships, and limited time. One wonders if a judicial body would be able to parse all of the information presented in a case and quickly make a decision before the ailing child's death.

What is the author's proposed method of guidance for savior sibling creation, use, and study?

STEP ONE: STANDARDIZED UMBILICAL CORD BLOOD BANKING

Umbilical cord blood banking has become popular amongst parents during the last decade, hoping that the stem cells contained in the cord blood can help their children in future. Yet Eilane Gluckman et al. from various European cord blood banking programs assert that for many families, private banking of their children's umbilical cord blood may be neither medically beneficial nor cost effective (2011, 1704). Another umbilical cord banking commentary found that some public banks like the New York Blood Center found matches for ninety-nine percent of patients and that 80% of cord blood donations were still available after ten years (Fox et al. 2008, 179). For comparison, the same commentary briefly discusses a popular private banking company that boasts 175,000 clients while only 38 of their samples

were accessed during a 14-year period. Furthermore, autologous umbilical cord blood donations may only be effective in 0.04% cases requiring transplantation (Fox et al. 2008, 179). This by no means is to say that parents should not bank at all, but rather to say that parents should be encouraged to donate their children's umbilical cord blood to a public repository where those in need of stem cells may search for matches for their ailing children. So long as materials are stored properly and that the identities of the donors are protected there should be no medical or social risk to the donor (Fox et al. 2008, 179). Besides, the amount of stem cells present in one umbilical cord may not be enough material for a transplant so the umbilical cord blood of one donor may have to be combined with samples from other donors before enough material is obtained.

Each state or county may have its own repository for banking. Each state could also use media campaigns to encourage parents who would normally discard their children's umbilical cords to direct the donation toward the public bank. At the moment, private banks encourage parents to independently bank for the sake of their own children. Perhaps the knowledge that public banks will aid in reducing the need to create savior siblings may provide additional incentive to direct donations to repositories that can be freely accessed by those who may benefit greatly (AAP 2007, 166). Parents may also be informed of the likelihood that a child's own umbilical may not provide the benefit that they once thought. Nevertheless, all parents could be asked before the child's birth if they would like to keep their child's umbilical cord and its contents or donate the tissue. If the parents do decide to keep the umbilical cord tissue, the tissue can be moved to a private storage facility at cost

to the child's parents. If the parents wish to donate the tissue, then the material can be placed in the local banking repository, with the parent's consent, for use by another child.

Why encourage umbilical cord blood banking? There are as many as four million children born in the United States every year (Martin et al. 2012, 1-2). Even though none of these children are registered as bone marrow donors, they could be. Because their genetic material could provide means to save lives, the names and genetic profiles of these children could be logged into a database so that these children can be contacted later in life to see if they would be willing to donate. Searching for donors would in fact be much faster because all registered children could be logged and categorized in a way that is accessible nationally. With the increased patronage of public umbilical cord blood repositories and meticulous cataloguing of prospective donors, better use could be made of material provided by children who already exist before pursuing the savior sibling process.

If the donation provided by a family were to go unused for a certain amount of time, the umbilical cord and its contents could be used for research purposes. Recall that the umbilical cord-derived stem cells are typically combined with bone marrow to obtain the correct volume of stem cells needed for transplantation. In a research setting, investigators could utilize unused umbilical cord-derived stem cells to develop ways of expanding the volume of transplantable material without having to combine samples from multiple donors or searching for a bone marrow donor. This research could also help savior siblings, because it could be used to stretch future stem cell and bone marrow donations. So in the future, if a child

needed to serve as a savior sibling, there may be a way to minimize the number of times the child's body would be accessed to obtain harvestable materials. In the far future, medical professionals may be able to do research that will allow for the creation of synthetic versions of stem cells so that the savior sibling process will be unnecessary altogether.

STEP ONE: STANDARDIZED IVF WITH PGD AND HLA MATCHING

Bioethicist Hank Greely believes that as technology improves and as IVF and PGD become less expensive, more people will take advantage of these processes when it comes time to procreate (Greely 2013). Greely refers to this as “easy PGD” and believes that this kind of childbearing will eventually replace natural conception. For couples who know that their collective genetic make-up increases the likelihood that their children will be afflicted, the offer of the use of technological intervention may be extended. One would also imagine that health insurance companies would find this method advantageous. They would pay less money in the long run if parents could start with children who lacked severe genetic ailments to begin with rather than paying to treat severe ailments after they have already developed.

Rather than birthing children whose purpose would be to serve as organ donors, the global community could encourage parents to use IVF with PGD and HLA matching to conceive in order to avoid birthing children with severe genetic ailments. If the obstetrician found the child to be genetically impaired *in utero*, parents would then have the option of aborting the child or continuing with the

pregnancy. In this way, parents could have greater control over the health of their children before conception.

Unfortunately, there may be therapeutic misinterpretations about the purpose of the technology. Parents may believe that because they have used PGD, their child will never become ill from genetic ailments and will exhibit the traits they want that child to have. However, the technology only screens for a limited range of genetic features and may not detect every possible ailment. Physicians and counselors would have to be vigilant in informing prospective parents about this limitation of the technology.

STEP TWO: GUIDELINES FOR SAVIOR SIBLING CREATION

The following guidelines are proposed for protecting savior siblings and collecting data about these individuals:

1. Proof of search for alternative possibilities – Parents and physicians must demonstrate to an oversight body or ethics committee that they have searched and exhausted all possible routes of obtaining a living donor, and that those attempts has proved unsuccessful. Providing proof of searching elsewhere will ensure that parents are looking for other alternatives, but it may also encourage physicians to try developing alternative to savior sibling creation.
2. Parents should be informed about the risks of being a savior sibling (including the likelihood of developing PTSD and psychosocial problems) and counseled about the ways that they can tell their savior sibling about the

reason for his or her conception. Parents could also be treated for distress suffered as a result of having a sick child, in case any trauma influences their decision making.

3. Parents should be informed that their child will be assigned a donor advocate whose job it is to advocate for the child during the savior sibling usage process (American Academy of Pediatrics 2010, 398). This advocate will stay with the child and help to explain any medical procedures the child will encounter, if the child is old enough to understand. If the child lacks the power of language, then the advocate will voice any concerns that he or she may have about the savior sibling's welfare.
4. Parents, savior siblings, and their families should be offered counseling to help cope with the ailing child's condition. Once the savior sibling is born, a system will be in place to talk with the child and to provide another system of support outside of the family to help manage any personal or interpersonal issues. The frequency of sessions can be adjusted but regularly scheduled or as-needed sessions are recommended, depending on the family's prognosis. If counseling sessions reveal that the donation process causes great distress to the savior sibling, this should be relayed to the donor advocate so that the savior sibling's role can be reassessed.

STEP TWO: GUIDELINES FOR SAVIOR SIBLING USE

5. Savior sibling donations should be restricted to self-regenerating bodily material such as blood, bone marrow, and hematopoietic stem cells.

6. After the savior sibling has made donations to his or her sibling, the donor advocate should make weekly visits during the recovery period and yearly visits afterward to monitor the savior sibling's well being. The collection of psychosocial data during these visits will allow medical professionals to understand how the savior sibling perceives the process and how the process may be changed for the future.
7. The savior sibling should begin regularly scheduled counseling sessions where counselors can work with researchers to maintain a database containing experiences of savior siblings.

How would the Two-Step guidelines look in practice?

RETURN TO THE SCENE

The medical team invites the Mason family back to the hospital to discuss the medical treatment plan. After consulting the hospital administration, the medical team feels assured that the hospital does not object to the procedure. Furthermore, the medical team and the hospital examine the Two-Step guidelines crafted for this case. Both parties agree to the contents. The team, however, wants to make sure that it has exhausted all other efforts before trying to create and use any savior siblings. The team informs the family that it will start to undertake Step One procedures for Samantha's cause since she has some time to wait.

When mothers come in to the hospital to give birth, they are asked to donate their child's umbilical cord blood to the county's repository. To help with the effort, the Mason family places ads in the local newspaper, does an interview with the local news

affiliate, and talks to the officials at Samantha's school so that the community can be involved in the effort to find a match for Samantha's treatment. Many people come into the hospital to be registered in the hospital's bone marrow donor's registry. As babies are born, parents voluntarily register their children in the registry list. Because of the registry, many parents with ailing children are able to find stem cell matches for their children. The Masons, unfortunately, are unable to find an adequately matched donor for their daughter. The medical team proceeds to Step Two.

The hospital assigns a counselor to meet with the family. A group of residents are assigned the case of Baby X, the savior sibling to be. The family is counseled about the limits of the use of IVF, PGD, and HLA matching. The family is also cautioned about some of the negative impacts of serving as a savior sibling and is informed of their ability to receive counseling as long as need be. The family will also be told that no long-term data exists to explain the farther-reaching impact of serving as a savior sibling. The family is then asked to participate in a long-term study where one of the medical team's representatives would check on the family, especially the health and welfare of the savior sibling. After counseling, the family will begin rounds of IVF treatment that will include PGD testing and HLA matching. Eight months later, Mrs. Mason learns that she is pregnant. Baby X is assigned a donor advocate and counseling for the family continues. Nines months later, Luca is born to the Mason family and he is a good match for Samantha. When Luca is born, the medical team harvests his umbilical cord blood and saves it. Luca's donor advocate continues looking through Luca's medical records and agrees that because the umbilical cord fluid is insufficient, another donation may be necessary. At three months of age, Luca provides a bone

marrow donation. The genetic material is processed and transplanted into Samantha. The medical waits a period of six months to study the effectiveness of this transplant to ensure that the treatment is working. All tests are clear.

The title of this thesis asks: “How can we save lives and protect savior siblings?” The answer is that each case of savior sibling creation and use must be studied casuistically to ensure that the savior sibling’s participation in the process poses the fewest risks and harms while providing benefit to the ailing child. Though the involvement of savior siblings is controversial, it is important to remember that the practice was born out of need and desperation, rather than malice. Medical professionals and ethicists should remind parents that this process may be beneficial to one child and detrimental to others. While there is not enough data currently in existence to provide concrete guidelines for savior sibling handling, the ability to study the experiences of these children will allow for the development of rules that could make the experience less traumatic. In short, the way to save lives and protect savior siblings is to ask and then listen to their opinions about the savior sibling process and make adjustments accordingly until near-perfect guidelines are developed.

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Curriculum Vitae

EDUCATION

Columbia University, School of Engineering and Applied Science

Bachelor of Science, Civil Engineering and Construction Management, 2012

Wake Forest University, Graduate School of Arts and Sciences

Master of Arts, Bioethics, expected December 2013

INTERNSHIPS AND EMPLOYMENT

Civil Engineer and Farm Manager, Cedar Farms, Accra, Ghana (Jun 2012-Present)

Researched means of recycling organic materials in vermicompost, designed a farm pond and natural debris filtration system for the pond's gaining stream, and assisted in decision-making regarding crop and building placement.

Legal Assistant/Intern, King's County District Attorney, Brooklyn, NY (Jan-Apr 2012)

Processed active cases and desk appearance tickets. Interviewed police officers, crime victims, and witnesses to determine facts of criminal cases. Prepared witness statements.

Legal Intern, Oasis Law Office and Consult, Accra, Ghana (Jun-Jul 2011)

Analyzed court documents and drafted preliminary responses to claims made by defendants and plaintiffs in family and corporate law cases. Filed paperwork in court and within the legal offices. Took notes during legal trials for managing lawyer.

Videographer, Columbia Technology Ventures, New York, NY (Jun 2010 - Apr 2011)

Filmed, edited, and posted lectures and interviews given by Columbia University professors.

Media Services Assistant, Columbia Video Network, New York, NY (Aug 2008 - Mar 2009)

Filmed course lectures for the Columbia Engineering Graduate School and assisted professors with in-classroom technology.

PROFESSIONAL MEMBERSHIPS

Engineer Intern (EIT), NY, Certificate Number 089116 (2012-Present)

American Society of Civil Engineers, Associate Member (2009 - Present)

American Society for Bioethics and Humanities, Student Member (2012 - Present)