

The Creation and Use of Savior Siblings
and their Violation of Human Rights

Elise Malehorn

Hilliard Bradley High School

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Abstract

This paper explores and explains the effects of savior siblings- children who are born out of pure use of their body organs and tissues to help save an older sibling with a terminal illness. The process of creation occurs through a variety of procedures and techniques. The savior siblings become donors of tissues and stem cells, among possible organ donation. The risks posed to the savior sibling- both prior and post birth- are overwhelming and pose no to little benefit for the older sibling after donation. A variety of legal cases are discussed and the legal actions taken against savior sibling creation are explained. The majority of the time, the diseases the older siblings possess are too rare and extreme to be treated. The intention of having a savior sibling usually comes from a place of desperateness and the main reason is not to fully love the child for who they are- just what they have to donate. The violation of human rights are discussed and how the creation of savior siblings can be ceased.

Keywords: savior siblings, donors, creation, diseases

Literature Review

Children who are born to be used for the donation of their tissues and parts to help save an older sibling, who has a terminal illness, are known as “savior siblings”. Savior siblings are born out of need by (often) desperate parents who want to save an older child- not for the sole reason of loving the unborn child. As treatment options have increased over the past half century in order to treat a variety of diseases, hematopoietic stem cell transplantation has become a standard medical care practice. Recently, when parents and doctors see fit, children will often serve as stem cell donors when a sibling is in need of a transplant. While this is monitored on a moderate level, the use of “savior siblings” has slowly began to become more popular in the past couple of decades (“Children as Hematopoietic Stem Cell Donors,” 2010, para. 1). The terminal illnesses that families deal with that commonly lead to savior siblings are Fanconi anemia, Black-Diamond anaemia, and a variety of different cancers (Berry and Engel, 2005, p. 1-4). When parents use savior siblings, the disease their older child has typically is on the more serious side of diseases. While the use of a savior sibling may give the older one an extended amount of time, the risks posed to the infant are too great to sacrifice for the older sibling. The review of recent literature suggests birthing a child in order for them to serve as a “savior sibling” does more harm than good for the unborn child.

Creating a savior sibling uses a lot of procedures and techniques in order to create the specific medial characteristics wanted, some that come with serious risks. The process begins with the use of preimplantation genetic diagnosis (PGD) which is used to determine an embryo’s

histocompatibility leukocyte antigen (HLA) to ultimately see if an embryo has certain medical characteristics such as tissue type, blood type, and a variety of stem cells. Once embryos are selected, in vitro fertilization (IVF) is used in order to insert the embryos into the mother's womb (Spriggs, 2005, para. 1). The majority of the time, PGD is used as a diagnostic technique in order to detect for genetic diseases (Devolder, 2005, p. 582). Some argue that, by using PGD to discard and select embryos when the unborn child is not benefitted, the diagnostic test is being misused (Devolder, 2005, p. 582). The harmful effects that are a risk to the embryos when using PGD are possible biopsy and freezing harm. Although the embryos may be screened for genetic diseases, PGD does not completely eliminate the possibility of the child having a genetic disease ("Benefits & Risks of PGD/PGS," 2016, para. 2). This procedure is mostly performed in private fertility clinics, who may have a possible bias toward positive outcomes of the procedure. While some successful outcomes have occurred, the unsuccessful trials are often not reported to the mass media (Trujillo & Surralles, 2015, p. 935). False hope is another misleading source when trying to create a savior sibling, along with the high expenses that come along with the process. The parents who are usually involved with savior siblings are in desperate need of a cure for their child and will do anything to save their already existing child.

Creating and birthing a savior sibling is not only dangerous for the pre-born child before birth, but also in the future. Once the savior sibling is ready to be born, the umbilical cord blood collection is the most common procedure done to gain access to stem cells ("Children as Hematopoietic Stem Cell Donors," 2010, para. 12). During the umbilical cord blood collection, one can change the delivery in order to achieve the maximum amount of stem cells collected. This is highly discouraged by the Institute of Medicine and the American College of Obstetrics

and Gynecology, who say there are too many possible risks posed to the newborn (“Children as Hematopoietic Stem Cell Donors,” 2010, para. 22). Additional risks to the donor after the stem cell collection can include the serious complications including bone, nerve, or tissue damage (“Children as Hematopoietic Stem Cell Donors,” 2010, para. 15). While the most common procedure performed on the donor child is a umbilical cord blood collection, some parents go as far as harvesting organs, such as kidneys, from the donor child for their older sibling (Devolder, 2005, p. 584). While it is rare for a younger child to donate organs, it becomes more common when the savior sibling reaches the pre-teen age (Devolder, 2005, p. 584). Donors may experience fatigue, headaches, and sleeping and bleeding problems if bone marrow is donated (“Children as Hematopoietic Stem Cell Donors,” 2010, para. 15). Once a person has donated certain medical tissues or organs, hardships may come along further in life. These hardships range from being restricted to a hospital bed to exclusions from childhood events, such as being restricted to what sports they can play, due to the risk of complications (“Children as Hematopoietic Stem Cell Donors,” 2010, para. 13). Data has shown that many child donors experience anxiety relating to their role, feeling has if they did not have a choice with the donation (“Children as Hematopoietic Stem Cell Donors,” 2010, para. 25). The possible risks to the savior sibling, both early and later in life, are not beneficial to the child and may cause more harm than good done in the end.

Legal cases associated with savior siblings have erupted more recently in the past couple of decades. The first public case of using a savior sibling first came into light in 1991, with the Currys. The Curry family used HLA typing to know the prenatal diagnosis and were ready to terminate the pregnancy if the embryos were not a match to the desired medical characteristics,

while eventually finding an embryo that fit their needs. Many embryos were discarded in the process, a sadly common practice when it comes to savior siblings (Devolder, 2005, p. 582). While the use of savior siblings are more common in the United States, other countries have taken precautions against the procedure. In 2002, Michelle and Jayson Whitaker of the United Kingdom were denied the license to receive this procedure on the grounds that the unborn child should not be exposed to the possible risks of using PGD, when in fact the technique does not have any direct benefit to the unborn child (Berry and Engel, 2005, p. 4). Ultimately, while a ban and refusal of this procedure is in place in countries like the United Kingdom, many often travel to the United States, where the practice often takes place in private fertility clinics (Berry and Engel, 2005, p. 4). One trial was performed dealing with HLA typing and PGD with a total of 7 Spanish families. The Spanish FA Research Network performed this study with families who have Fanconi anemia either themselves or in their heredity. Throughout the study, every couple had an average of about 5 IVF cycles and about 43 embryos selected on average. Out of the 7 couples, only 5 pregnancies occurred. As a result, only 1 baby was born with 4 pregnancies failing. Therefore, the IVF cycle success rate was only about 2.6%. One couple even had as much as 158 embryos selected and 7 embryos transferred to the womb, with no pregnancy resulting. With the given results from the study, the Spanish FA Research Network came to the conclusion that more than 95% of IVF cycles will fail in resulting in a birth when dealing with families with Fanconi anemia (Trujillo & Surralles, 2015, p. 935-937). The low success rate and variety of procedures used create an extreme risk to the unborn child. With the overall outcomes of multiple different cases, the use of savior siblings takes more of a risky path for the unborn child than one with success.

Evidently, the use of savior siblings creates too many possible risks to the infant with no little gain for the older sibling. With the use of all three techniques used- HLA typing, PGD, and IVF- the potential risks and effects on the savior sibling outweigh the possible benefit of the little time that might be added to the older sibling's life. A child should never be born out of anything but love for who they are, not what they have to offer. By putting the unborn child's life into danger between the performance of multiple procedures and donations, the savior sibling is no longer being treated like a human being- just a source for tissues and parts. The possible ways to stop savior sibling creation can be as simple as making people aware that this is occurring. While the parents who go through this process are majority of the time desperate and in a dark place, these reasons do not hold up a valid rationale of bringing a child into the world when it is not solely for the unborn child's benefit. Another possible solution can be using the Universal Organ and Blood Donation list instead of birthing a child for the sole need of tissues. The organs and tissues on the universal list are from donors or deceased; people who are willing or no longer need their donations. Donation of money to organizations who are dedicated to finding cures to these terminal diseases, like the Kidz1stFund who is dedicated to finding a cure to Fanconi anemia, are another way the average person can help. The terminal illnesses that these types of children have are very serious and a cure would save many lives. When it comes to savior siblings, the general effect that bringing a child into the world for the wrong reasons can take are stronger than one can imagine- both on the child and family. The possible miracle of an older child living a couple more years does not outweigh the harm that can come to an infant for using him or her for only their tissues and parts, when the main intention is not to love them fully for who they are on the inside.

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