

Saviour Siblings

Aim: To define the term 'saviour siblings' in a new light by looking at some of the ethics surrounding this topic in hope to educate the general public.

Audience: General Public

Reason of choice:

- I want to inform people about saviour siblings to give them a better, fairer ground to propose judgement on the issue by following one case study of the Nash Family.
- Saviour siblings was one particular aspect of the module which was touched on but didn't deepen the analysis. Out of interest, I decided to explore it further.
- I chose to present my work in the form of an art piece because I believe that in order to capture the public's attention, visual display is powerful and allows the viewer to reach their own conclusions as they try to engage with the message being conveyed.

Art piece (please look, also listen to the audio attached):

- Hands – to show support between 2 siblings
 - Right hand represents the 'sick sibling' with intravenous cannula.
 - Left hand represents the 'saviour sibling'.
 - Each wrist is displaced by abstract-DNA to exemplify the notion of creating saviour siblings with 'healthy DNA' (green) and 'diseased DNA' (red). This further indicates something they both share but has gone wrong in one sibling.
 - I chose the colour red for the sick sibling because it's a strong, emotionally intense colour, usually associated with danger and green is a colour of nature which symbolises safety, healing and endurance [1]. Also, I was inspired by Dr. Denny's presentation when he talked about GATTACA (film). He demonstrated that in GATTACA, they used colour exploration of "valid/invalid binary" through the use of green-red colours, respectively.
- Gold background with internal love heart
 - Gold as we know it is a precious metal and I chose this colour to demonstrate the delicate situation and to represent a valuable moment of sibling love [2].

- According to 'Colour Matters', yellow is associated with happiness and optimism [3].

Saviour siblings is apparently a topic that is not well spoken about. I have attempted to demystify the ethical concerns raised by investigating the matter using different platforms to reach a middle ground. In general, the arguments around saviour siblings are based in three issues: the notion of creating a saviour sibling, slippery slope argument which implies that saviour siblings will lead to the creation of 'designer babies' and lastly, child welfare.

Below are different sections I felt was important to look into...

What is a saviour sibling?

A saviour sibling is a brother or sister created through selective in-vitro fertilisation (IVF) which involves tissue typing and pre-implantation genetic diagnosis (PGD)[4, 5] to serve as a potential organ/stem cell donor to their existing sibling with a rare and terminal disease.

Public's View:

To understand people's opinions on the matter, I have interviewed randomly selected individuals from the general population. Heather (Minister of Religion) was unsure of what the term 'saviour siblings' meant. After informing her, she replied saying "*I am totally against the idea of putting a child through unnecessary stress in an attempt to save another. It is unacceptable to use a baby to benefit the one that's already suffering. As harsh as it may be, let the sick sibling die naturally*"[6].

Surprisingly, many people in the older generation shared the same opinion as Heather. In light of this, I wanted to see if the younger generation would have a different opinion. Dylan (student) also was unsure of the subject and after unbiasedly communicating to him the topic, he responded, "*It is a great idea [because you are saving a child's life]. No parent wants their child to die so I understand why they would do this. I am okay with it as long as the procedure does not inflict pain on the saviour sibling and it is safe*" [7]. I further asked about his opinion

on using IVF to create the sibling and he said *“I think it’s good that you are eliminating as much risks as possible to ensure that the saviour sibling is a perfect match [to the sick one]”* [7]. However, some students took the religious approach of ‘playing God’ and that you should ‘accept and love the child the way they are’. From this, I was inspired to explore the difference of opinion.

My Sister’s Keeper (movie)[8]

Jodi Picoult wrote the novel which was translated into a movie based on a real life story of the Nash family [9]. In the film, 13 year old Anna Fitzgerald, sues her parents for ‘medical emancipation’ to challenge her parents for free will to not donate her kidney to her older sister that has acute leukemia (bone marrow cancer resulting in abnormal white blood cells)[10]. Anna’s mother in the movie illustrated some struggles she went through to try and keep Anna’s sister, Kate alive. Kate, became the sole focus of the family and to some extent Anna appeared to be neglected. This movie raised a lot of ethical concerns [11] that were projected to the actual family, some are discussed below...

Exploring ethical controversies:

Psychological impact of saviour siblings is a topic for debate. Janelle Mills investigated *‘how does knowing one’s status as a sibling affect a child’* and found that it can be positive and/or negative [12]. A positive outlook was seen in Jamie Whitaker born in 2002 to save his older brother Charlie from Diamond Blackfan Anaemia (DBA) [13]. DBA is extremely rare and is characterised by the inefficient production of red blood cells. Jamie reported that he was ‘happy’ about the reasons he was conceived and doesn’t ‘feel like a superhero’. He also mentioned that he knows his parents ‘want’ and ‘love’ him [12]. However, many people dispute this. In fact, the Nash family news, caused a media outcry with some referring to Adam Nash as the “Little Frankenstein”[14]. Adam Nash is a saviour sibling, conceived to save his older sister Molly Nash from a life-threatening genetic disorder of bone marrow deficiency known as Fanconi anaemia [15]. Their story inspired ‘My Sister’s Keeper’.

Amanda Faison, Senior Editor of 5280 Magazine is the author of “The Miracle of Molly”. She spent 9 months with the Nash family to write the story and wanted ‘an emotional connection’ to be portrayed to the public so that the reader can see the dilemma from the family’s

viewpoint. She admitted that it was 'difficult' reading the novel (*My Sister's Keeper*) as she felt the book presented the 'worst-case scenario of the actual story' [16].

Moreover, Molly's mother, Lisa Nash was interviewed in 2009. Disheartened, she mentioned that the movie did her family some 'disservice' and she further wished that the movie was never made. She explains that the movie line of Anna saying, "Most babies are accidents, not me. I was engineered. Born to save my sister's life", negatively impacted her. "How horrible for a child to think that! Adam would never think that!", she protests [17].

In a recent interview by Denver channel, Lisa opened up explaining that she wanted to do everything possible to save their daughter. "If it was you in my shoes, you would react differently ... Good for you that you could watch your child die and not do something", she exclaimed [18].

In a like manner, the controversial nature of this topic escalated in the UK (United Kingdom) leading to MPs debating on the 'saviour sibling ban' in 2008. Tory David Burrowes was against the concept mentioning that it was wrong to 'create a child for the benefit of another, regardless the need'. However, the Human Fertilisation and Embryology Bill allows embryo selection if a tissue match is positive for the sick sibling. In addition, Dr Evan Harris (former Liberal Democrat science spokesman) addressed the ethical implications of the issue and concluded that there's no burden on the saviour sibling as there's no evidence illustrating this. But, "there is evidence that if they are not born in this way then they will suffer bereavement because the older child may die" [19]. Sheldon et al supports this statement as they concluded that "...selection of saviour siblings should be permitted, especially given that prohibiting it would result in the preventable deaths of a number of existing children."

The argument of 'designer babies & slippery slopes' suggests that saviour siblings would be the first step to permit parents to choose characteristics of their baby that doesn't serve a purpose in their health, such as eye or hair colour [4]. However, I think that there will always be an ethical barrier when it comes to biotechnological developments and this argument exists because of the 'fear of over-using technologies' [20]. To overcome this we must adapt with the advancements. In fact, this is one of the reasons why summits like BEINGS

(Biotechnology and the Ethical Imagination: a Global Summit) are held to re-evaluate the current status of cellular technologies and their future use [21].

My Opinion:

At the start of my research, I was leaning towards being *against* saviour siblings. However, when reflecting back to how I feel now, I am neutral. This is the very reason why I chose to tackle this issue by considering different opinions. I learned that with additional information I was able to consider the *'for'* side and simultaneously develop empathy for both sides (for/against).

However, I think that as soon as the saviour sibling is showing signs of distress, medical professionals should intervene as I believe they (saviour siblings) have rights over their parents when it comes to this. Also, I think it's important for the Government to regulate the rights of parents with caution so they don't take advantage of their children.

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