Are Saviour Siblings a Special Case in Procreative Ethics?

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Abstract:

Children conceived in order to donate biological material to save the life of an already existing child are known as 'saviour siblings'. The primary reasons that have been offered against the practice are: (i) creating a saviour sibling has negative impacts on the created child and (ii) creating a saviour child represents a wrongful procreative motivation of the parents. In this paper we examine to what extent the creation of saviour siblings actually presents a special case in procreative ethics. Although we do not deny that there is a unique feature present in the saviour sibling case—namely, that the child was created to save their sibling's life, we argue that the distinctive feature of *being a saviour sibling* does not make the procreative act wrong. Our claim is that the features that would make the creation of a particular saviour sibling (im)permissible are the same features that would make the creation of *any* child (im)permissible. Our conclusion is that saviour siblings—in relation to the reasons for the (im)permissibility of their creation—are not a special case for procreative ethics.

Introduction

Hematopoietic stem cells are found in bone marrow and umbilical cord blood, and transplants offer sufferers of certain types of leukemia and anaemia an excellent chance of surviving an otherwise terminal disease. However, stem cell transplantation requires a donor that is a Human Leukocyte Antigen (HLA) match to the recipient and given the small size of modern bone marrow donor programs, the odds of a match are often miniscule. For instance, in the United States there is a roughly 0.25 percent chance that an unrelated individual will be an acceptable match. Odds of a match improve to twenty-five percent for siblings since they both inherit the same HLA genes from their parents, but due to the average size of the modern family in the West, this means that sufferers of leukemia and anaemia will usually lack an existing sibling match. As a result, parents of children suffering from these diseases may wish to conceive a child to provide the necessary stem cells from the newborn's umbilical cord blood to save the life of their existing child. Modern technology means that parents do not need to just conceive and hope to hit the HLA jackpot. Rather, they can use in vitro fertilization (IVF) to produce multiple embryos and follow up with preimplantation genetic diagnosis (PGD) to select one or more that are an HLA match for the sick child.² At birth the cord blood is collected from the umbilical cord and transplanted to the sick child. This is curative in up to ninety percent of non-cancer patients and has a five-year survival

¹ Robertson et al., "Conception to Obtain Hematopoietic Stem Cells," 35.

² Preimplantation Genetic Diagnosis (PGD) is the genetic profiling of fertilized embryos for certain characteristics (like HLA type or inherited conditions like Huntington's Disease) before they are implanted.

rate (the benchmark for cancer remission) of at least sixty-eight percent of patients with leukemia.³ In both cases, the chances of survival are more than doubled by using a related rather than unrelated donor.

Children conceived in order to donate the stem cells in their cord blood are examples of 'saviour siblings,' a term referring to children intentionally created to donate biological material, most commonly cord blood, but theoretically also bone marrow or solid organs (liver and kidney), to save the life of an already existing child. Some writers in medical ethics have argued that there are features inherent to the creation of saviour siblings that make the practice impermissible, or which should at least make us skeptical about the arguments offered in its favour.⁴ The primary reasons that have been offered against the practice are: (i) creating a saviour sibling has negative impacts on the created child and (ii) creating a saviour child represents a wrongful procreative motivation of the parents. In this paper we examine to what extent the creation of saviour siblings actually presents a special case in procreative ethics. We do not deny that there is a unique feature present in the saviour sibling case—namely, that the child was created to save their sibling's life. We also do not claim that this unique feature raises no novel normative questions for procreative ethics (e.g., whether there are any conditions under which the creation of saviour siblings might be morally obligatory). But what we do deny is that the distinctive feature of being a saviour sibling is what makes the procreative act wrong. Our conclusion is that what would make the creation of a particular saviour sibling (im)permissible are the same things that would make the creation of any child (im)permissible. Our conclusion is that saviour siblings—in relation to the reasons for the (im)permissibility of their creation—are not a special case for procreative ethics.

There are two clarificatory points to make at the outset. First, our discussion relates to saviour siblings created to donate umbilical cord blood, bone marrow, and/or solid organs. However, due both to continual improvements in the efficacy of cord blood transplants and the availability of a cord blood donation at the time of birth, we take cord blood donation to be the prototypical saviour sibling case.⁵

Second, in order to determine whether or not saviour siblings are 'special', we need to know what the relevant comparator is—special compared to what? Since we are interested in whether or not saviour siblings present a special case of *procreative* ethics, the relevant comparator is what we will call the *Standard Child*. This is a child created (in part) for any number of non-

³ Leung et al., "High Success Rate of Hematopoietic Cell Transplantation Regardless of Donor Source in Children with Very High-Risk Leukemia."

⁴ Wolf et al, "Using Preimplantation Genetic Diagnosis to Create a Stem Cell Donor"; Chan and Tipoe, "The Policy Statement of the American Academy of Pediatrics."

⁵ To elaborate, multiple studies have found that sibling-matched cord blood transplantation can be just as effective in treating blood diseases/cancers as bone marrow transplants, with possibly fewer complications. See Rocha et al., "Graft-Versus-Host Disease in Children Who Have Received a Cord-blood Or Bone Marrow Transplant from An HLA-Identical Sibling"; Bizzetto et al., "Outcomes after Related and Unrelated Umbilical Cord Blood Transplantation for Hereditary Bone Marrow Failure Syndromes other than Fanconi Anemia"; Locatelli, "Outcome of Patients with Hemoglobinopathies given either Cord Blood or Bone Marrow Transplantation from an HLA-Identical Sibling." And so, given that the median time between beginning the first cycle of IVF-PGD and the birth of a saviour sibling is 3.7 years, and young babies cannot donate bone marrow, it is expected that a cord blood donation would be performed in the first instance, with the possibility of needing a bone marrow donation later on if the cord blood transplant were unsuccessful. See Kakourou et al., "Pre-Implantation HLA Matching," 80-81. Thus, saviour siblings would not be created to *be bone marrow donors*, but to be cord blood donors, with the knowledge that there may be bone marrow donation at a later date. And the same point applies to organ donation, since given that living solid organ donation by a savior sibling could only ever occur many years after their creation. This means that in the saviour sibling case, bone marrow and solid organ donations, *contra* cord blood donation, are only possible, not inevitable scenarios.

saviour reasons, like the parents' desire to have a(nother) child or provide companionship to their existing child(ren), please grandparents, and so on (more on these reasons in Section II). It is our contention that being a saviour sibling does not raise special normative concerns relative to the *Standard Child*. Finally, to ensure we do not stack the case in our favour, in the saviour sibling case we will have in mind the scenario where parents would not otherwise have chosen to have an additional child.

1. Negative Impacts on the Saviour Sibling

Physical Harm

The first and most obvious reason to regard saviour siblings as a special case of procreative ethics is to claim that their creation harms the created child, and that such harm is not present in the creation of non-saviour siblings. Such harm, the argument might go, could be sufficiently serious that it makes the creation of a saviour sibling unjustified, regardless of any benefits it might afford the sick child.

The first point to make is that the special harm cannot be from the use of IVF and PGD in the selection process itself as these treatments are not unique to the saviour sibling case. IVF is used around the world by infertile and LGBT couples and PGD is available to families with a history of inherited diseases such as Cystic Fibrosis and Huntington's Disease to select for children who will not suffer from these serious and often fatal conditions. If there is any harm affiliated with IVF and/or PGD *per se*, there is a harm for *all* embryos created/selected in this way.

When it comes to physical harm *after* birth, we will first consider cord blood donation.⁶ The case of cord blood donation is simple because this procedure results in no physical harm at all. The collection of cord blood is non-invasive, painless (it is taken from the placenta after it is delivered), and studies have shown that there is no risk to the newborn to collect this blood.⁷ And so, while this brings in a difference (not all children have their cord blood collected, although the vast majority could), it is not a difference that is relevant to a claim that the creation of saviour siblings is a special case of procreative ethics.⁸ Indeed, thousands of mothers, including one of the authors, voluntarily donate their newborns' cord blood to strangers via public blood banks every year and others collect and store it in case it is needed by their own child in the future.

However, if the saviour sibling case is one where bone marrow or solid organs end up being donated, then physical harm will occur, as these donations are more physically invasive and, in the case of solid organs, can require significant recovery time. While this might make the saviour sibling case initially appear very different from the *Standard Child* procreation case, this would be too quick. This is because any tissue donation is only ethically permissible under certain conditions, and these conditions apply just as much to a saviour child as to the *Standard Child*.

For example, the American Association of Pediatrics (AAP) has laid out the criteria under which it is ethical for pre-competent minors to donate bone marrow, and these criteria would need

⁶ Of course, there are those who believe that *any* procreation harms the resulting child since every life will inevitably include some elements of pain or suffering, such as Benatar, *Better Never to Have Been*. But this is also not special to the saviour sibling case.

⁷ Rubeis and Steger, "Saving Whom?" 480-81.

⁸ Mother-baby dyads who cannot give cord blood include those with inherited medical conditions or infectious diseases, babies conceived by donor eggs/sperm, twins/triplets, and babies born more than six weeks prematurely.

to be in place regardless of whether the child was created as a saviour sibling or not. Similarly, any organ donation (and its affiliated harms) is only ever ethically permissible when the patient has given their informed consent. These requirements will apply just as much to the saviour sibling case as they will to the *Standard Child* – they are not trumped by a saviour sibling's reason for genesis.

One might think, however, that there is still a difference in the sense that the saviour child is being created *in order* to be a bone marrow/organ donor and therefore experience pain. To this we have two replies. The first is to point out that it is not actually the case that the child *is* being created in order to donate and experience pain. For one thing, they are being created in order to save their sibling. But given cord blood is the only *inevitable* form of donation (see note 5), then a better formulation of the objection is that they are being created *with the knowledge* that they may later donate and therefore experience pain/harm.

But this possibility that the child will experience pain/harm is not enough to claim saviour siblings are special. Anytime you choose to create a child you do so in the knowledge that they may be harmed and/or experience pain in the future. The question is whether there is anything special about creating a child you know may experience pain *in this particular way*—viz. as a future bone marrow or organ donor—as opposed to a multitude of other ways (car crashes, sports injuries, broken hearts). One difference might be that in the tissue donation case, the pain/harm will be experienced for the benefit of another. But this can be true for the *Standard Child* too. He could be injured in a car accident on the way to take his sibling to a sports practice or dentist appointment. Another difference might be that the pain/harm is not totally random, but perhaps reasonably foreseeable. However, this could also be true for the *Standard Child* who is created and strongly directed by her parents to play sports like ice hockey, rugby, or horseback riding that have a high probability of (sometimes serious) injury.

Psychological Harm

Perhaps what makes the saviour sibling case special is that it leads to psychological harm for the created child that would not be present in the *Standard Child* case. Of course, it is impossible to predict what the psychological well-being of *any* child will be before conception, and this is equally true of saviour siblings. But in both the saviour sibling case and the *Standard Child* case, two features seem relevant to any prediction about psychological harm: the child being informed for the reason for their genesis, and the nature of the parents' attitudes to/treatment of the child. We consider each in turn.

Let us assume that a saviour child is informed of their reason for genesis. They will grow up knowing they were created in order to save their sibling. What might the psychological impact of that be? Critics might think it could lead the child to fail to see herself as a person with dignity

⁹ The criteria are: (1) No adult matches are available; (2) There is a strong, positive relationship between the donor and recipient; (3) There is some likelihood that the recipient will benefit from the transplant; (4) The risks to the donor are minimized and reasonable in relation to the benefits accrued to the donor and recipient; (5) Parental (and sometimes donor) consent is obtained. See Ross et al., "Children as Hematopoietic Stem Cell Donors."

¹⁰ Radcliffe Richards, "A World of Transferable Parts," 381; Saunders, "Consent and Organ Donation," 312-13. In addition, almost all legal jurisdictions have lower age limits on living organ donors, usually sixteen years. Where there are no limits (e.g., England), there is still a requirement for informed consent. This suggests what would be concerning in the organ donation case is if being created as a saviour sibling influenced informed consent. We consider this below ('Violations of Autonomy').

who is worthy of respect. They may feel as though they were not *really* wanted by their parents, or that their parents took on an unwanted burden in having them. But similar sentiments could also occur in many forms of the *Standard Child* case. Take for example children who are the result of a contraceptive failure or sexual assault. These children, upon learning the cause of their creation, will surely be just as likely as (if not more than) saviour siblings to feel they were not *really* wanted by their parents. But the point here extends beyond only 'unplanned' cases of procreation. This is because, as we will outline in more detail in the section on wrongful parental motivations, it is not only conceptually impossible to create a child purely for their own sake (because no specific child exists at the point of conception) but doing so is also morally undesirable (because some instrumental value is key to positive personal relationships). This means, in principle, that there is always the potential for a child, upon coming to learn of the reason for their existence, to feel as if *they* were not *really* wanted by their parents (say, because they were created to give an older child a sibling, or to pass on genes, or due to personal fulfilment from parenting, and so on).

However, a different worry about psychological harm could be that the saviour child might feel like a failure and have low self-esteem if their donation did not save their sibling and they died anyway (even though this is unlikely due to the very high success rates), and that no such potential sense of failure is possible in the Standard Child case. But an individual's self-esteem, and any lack thereof, cannot be read directly off how they fare against some standard taken as important by third parties. This is because self-esteem, as a self-regarding attitude, is dependent on a person's own beliefs about what standards are important, and how they fare against them. 11 As such, insofar as it is possible that children in the Standard Child case believe that they fail to live up to their parents' expectations or act in a way consistent with the standards related to the reason for their creation (which, to them, the meeting of which will likely be very important), then a similar concern with a sense of failure and of feeling like they disappointed their parents applies just as much in their case too (even though to others the standard might seem less important than the one in the saviour sibling case). Taking one of the common reasons for procreation just mentioned, if a child knew the reason for their existence was to give their older sibling a friend, but ended up being disliked by their older sibling, then possible psychological harm resulting from hits to their self-esteem and letting down their parents seems just as likely.

Of course, it is undeniable that saviour siblings might experience psychological harm not only from being informed of the reason for their existence, but due to the way they are treated by their parents. Examples might include parents treating them as an unwanted burden, regularly reminding them that they did not really want them, or visibly favouring the older child. But these poor parental behaviours could sadly happen to *any* child. Children in the *Standard Child* case can also be subjected to similar treatment, such as being told they were an 'accident,' or that they are a burden and that they make their parents' lives so much harder, and so on. It seems to us that in both these cases the wrong is in the parents having related to their children (saviour or standard) in negative ways or taken certain negative attitudes towards them. Any cause of psychological harm for the saviour child is not that they were created to be a saviour sibling as such, but due to the negative way(s) in which the parents relate to the child as they grow up. Whether *any* child feels loved and grows to see themselves as a valuable end in themselves depends substantially on how they are treated by their parents; saviour siblings are not unique in this respect. The same point applies to other kinds of non-physical harm that might potentially be experienced by the saviour sibling, such as receiving less material benefit or fewer opportunities relative to the older

¹¹ Sachs, "How to Distinguish Self-Respect from Self-Esteem"; Dillon, "Self-Respect and Self-Esteem."

child. Such harms are contingent on the actions of the parents; they are not inherent in being a saviour sibling.

However, one might object that although these potential psychological harms can happen to any child, they are more likely for saviour siblings than for other children. We disagree. Although there is always the possibility that parents will treat their saviour child badly (which, as we have said, is unfortunately a possibility for any child), we think this is, at worst, equally likely and, at best, much *less* likely to be experienced by a saviour child. It would be a strange person indeed who cared so deeply about their first child that they were willing to conceive, bear, and raise another child to save them, yet also be so callous and unloving towards the second, saviour child to whom they stand in exactly the same biological and parental relationship as the first. Indeed, in studies investigating the attitudes of parents who decided to create a saviour sibling, parents flatly rejected the idea that any person who was willing to go through IVF and PGD could then mistreat the resulting child or treat them differently from the older child. ¹² If anything, then, it seems more likely parents of saviour siblings will treat them in a way that makes them feel like a *hero* because they did something no one else could do—save their brother or sister. These children may well embrace their identity as a saviour sibling as a badge of honour.

Violations of Autonomy

The next potential reason saviour siblings might present a special case for procreative ethics is that their creation violates the saviour child's autonomy. If violation of autonomy is understood to be things being done to a person without their consent, then perhaps creating a saviour sibling to donate stem cells violates their autonomy. ¹³ In these cases the donor child is far too young to grant or withhold their consent to the donation and the procedure relies on the consent of the parent. In medical ethics this is known as the stage of pre-competence. Some critics move directly from the inability of a saviour sibling to give consent to the procedure, to a claim that, as a result, the procedure constitutes a direct violation of the child's autonomy in a way that counts against the permissibility of the practice. ¹⁴

In relation to cord blood, the first point to make is that the mere fact a saviour sibling does not consent to the donation of cord blood cannot serve as an argument that saviour siblings are special because it mirrors the uncontroversial and not uncommon practice in the *Standard Child* case of parents choosing to donate their newborns' cord blood to public cord blood banks. This aside, it is doubtful that on its own the lack of consent to an action that incurs no physical harm and no increased likelihood of psychological harm (like cord blood donation), is sufficient to constitute a violation of the autonomy of a pre-competent child. This position would commit one

¹² Strong et al., "It's Time to Reframe the Savior Sibling Debate," 19-20; Haude et al., Factors Influencing the Decision-Making Process and Long-Term Interpersonal Outcomes for Parents Who Undergo Preimplantation Genetic Diagnosis for Fanconi Anemia," 651.

¹³ This point does not apply to organ donor saviour siblings because organ donations ethically and legally require a person's informed consent.

¹⁴ Rubeis and Steger, "Saving Whom?" 480; Chan and Tipoe, "The Policy Statement of the American Academy of Pediatrics," 3.

¹⁵ One objection here might be that a relevant difference is that parents of saviour sibling are likely to be biased when it comes to a decision over donation, given this is the very reason why they decided to have the child in the first place. But if parental bias was a relevant difference (which we are not sure is likely, see above), it is more of a concern with using parental consent as a proxy for a child's best interests (which also occurs in the *Standard Child* case), not a concern that the creation of saviour siblings and subsequent donation cannot be in the interests of the child.

to regarding virtually all actions towards pre-competent children, including the completely innocuous, as violations of their autonomy. But this cannot be right. You do not violate your pre-competent child's autonomy when you change their nappy or take them with you to the supermarket in the absence of their consent. With regard to bone marrow donation, there is no autonomy-related difference between saviour children donating and the *Standard Child* donating. In both cases certain criteria (at the moment the accepted criteria are those of the AAP—see footnote 9) will need to be met. If donating bone marrow wrongfully violates a child's autonomy, then that is wrong whether that child was a saviour sibling or not.

An alternative objection might be that saviour siblings did not consent to being created for the purpose of their donation. Might this be a relevant difference to the Standard Child case? Not if consent is understood as express consent due to the simple fact that nobody consents to the reasons for their own creation. The argument might, however, be put in terms of hypothetical consent and go something like the following: While I might hypothetically consent to being created for the array of purposes that make up the *Standard Child* case, I would not hypothetically consent to being created for the purpose of donating my stem cells to save my sick older sibling. This is plausible, but it is not clear that the concern here is still with autonomy. This is because to make a statement about hypothetical consent, we need to talk of the reasons why such consent would or would not be hypothetically given. But once we are talking of reasons, it is unclear what work hypothetical consent is actually doing in the argument. If it is some reason x which makes us say that a person would not hypothetically consent to being created as a saviour sibling, then it is that reason that provides the argument against the practice, a person's hypothetical consent provides no independent argument.¹⁷ To claim saviour siblings are a special case due to a lack of hypothetical consent then, is not to claim that creating saviour siblings is special due to its effects on the created child's autonomy, but that it is special for some other reason.

Perhaps creating saviour siblings is normatively different from the *Standard Child* case due to it affecting the autonomy of the child in the future. For instance, Matthew Clayton argues that actions toward a minor violate their autonomy if, once they have reached a stage of competence, they would denounce the treatment. That is, what counts is *retrospective* consent. The cases that Clayton thinks are problematic are those that can be seen as deciding for the child the goals they will pursue later in life. Similar concerns underlie the claim that children have a right to an 'open future,' which requires key options to remain open until a child is a self-determining adult who can choose among them. An example Joel Feinberg gives is Amish parents refusing to send their children to public schools, given this drastically limits the occupational choices that will be available to them. ¹⁹ This focus on a child's future autonomy is more appealing than making a wholesale claim about all actions in the absence of informed consent being violations of autonomy,

¹⁶ This does not deny arguments claiming children (even young children) possess the capacities relevant to autonomy. See: Mullin, "Children, Autonomy, and Care"; Hannan, "Childhood and Autonomy," 115-18. The saviour sibling case relevant here (cord blood donation) concerns actions towards children that are pre-competent infants. We are not aware of any argument that claims these children possess autonomy.

¹⁷ As Ronald Dworkin puts it: "hypothetical contracts do not supply an independent argument for the fairness of enforcing their terms. A hypothetical contract is not simply a pale form of an actual contract; it is no contract at all." See "The Original Position," 17-18. David Enoch has recently argued (in "Hypothetical Consent and the Value(s) of Autonomy") that hypothetical consent might be normatively significant and be connected to the value of autonomy in situations where it better respects a person's deep and central commitments. As we are about to argue, we do not think the saviour sibling case connects to autonomy so understood.

¹⁸ Clayton, "The Case against the Comprehensive Enrolment of Children."

¹⁹ Feinberg, "The Child's Right to an Open Future," 77, 81-82.

as it explains why certain innocuous actions are not violations of autonomy (taking your precompetent child to the supermarket) while others plausibly could be (taking your pre-competent child to be baptized).

Does the creation of a saviour sibling to donate cord blood and possibly bone marrow fail to respect a child's future autonomy in a way the creation of the *Standard Child* does not? We think not. The medical procedure does not lock a child into a particular way of life before they get the chance to choose for themselves, nor does it close off a set of key options. From the perspective of future autonomy, being created for the purpose of stem cell donation is less like the actions Clayton and Feinberg find problematic and more akin to the multitude of actions that are permissible to do to a pre-competent child unable to give their consent, such as choosing their hairstyle, giving them a well-tested vaccine, or taking them with you on a car ride. Just like haircuts, vaccines, and car trips, donating stem cells does not fix the options or limit the horizons available to children once they become competent to choose for themselves.

However, an argument might be made that creating a saviour sibling and donating their cord blood *is* changing the likelihood of a child's future choices in one important respect—future donations (including more invasive or permanent donations to their sick sibling such as solid organs like the kidney or liver). The worry is that a saviour sibling may be pressured later in life to donate again if their sibling relapses or develops new illnesses, and that this pressure would constitute a violation of autonomy (a similar concern will apply to any child who is the candidate to save a loved one's life through donation). This concern then overlaps with the worry briefly signalled earlier (note 10) regarding the organ donation saviour sibling case, and the thought that being created for this purpose might have an effect on informed consent by putting undue pressure on the child (who has reached a stage of competence) to donate.²⁰

A common view in bioethics is that for a patient to give their informed consent to a medical procedure, they need both to have an adequate understanding of the risks involved and, perhaps more relevant to the discussion here, to be free of any kind of 'controlling interference,' where controlling interference is understood as the active intervention by other agents.²¹ Similar accounts put normative weight on informed consent out of it ensuring patients are able to make self-authored decisions that are the result of their own judgement and reflection, making them responsible for the shape of their own life.²²

Three barriers to this aspect of informed consent commonly identified are: coercion, undue inducement (positive offers clouding rational judgement), and 'no choice' situations.²³ Is a saviour sibling's choice to donate an organ particularly vulnerable to any such barriers? If these barriers occur due to problematic behaviour and actions of parents, then this will of course fail to be a case of informed consent. But this just becomes another instantiation of the non-physical harm case. It is of course possible for a saviour sibling to feel pressured to donate because of threats received from their parents, but coercion and threats (even implicit ones) to undertake serious life decisions (like donating a solid organ) are serious parental wrongs that violate a child's autonomy, regardless of whether a child is a saviour sibling or not. So are actions aiming to 'nudge' a child into making one decision over another (say by intentionally influencing a child's decision about donation by

²⁰ Once a child has reached a stage of competence, it would be wrongfully arbitrary to treat their voluntary decisions regarding donations any differently than voluntary decisions of competent adults. Of course, the safeguards to ensure the decision to donate is in fact voluntary might still differ between competent children and adults. See Wilkinson, *Ethics and the Acquisition of Organs*, 138-44; Brierley and Larcher, Organ Donation from Children," 1178.

²¹ Beauchamp and Childress, *Principles of Biomedical Ethics*, 100-1.

²² Dworkin, The Theory and Practice of Autonomy, 108ff.

²³ Eyal, "Informed Consent"; Campbell et al., "How Young is Too Young to be a Living Donor?"

beginning and ending all conversations with how fantastic it would be if they donated), or framing the issue as one which makes the child feel as if there is really only one choice to be made ("Once you have undergone the donation...").

What we take to be the more serious charge is the concern that even if a saviour sibling is raised in a loving environment which inculcates in them a strong confidence in their individual worth, the mere fact that they are a saviour sibling might put undue pressure on them that influences their decision to donate an organ. Perhaps this fact is enough to make the decision to donate an organ to save a loved one appear as a 'no choice' situation. The thought is that because the choice not to donate is such a horrible alternative (because it results in one's sibling dying), the voluntariness of the choice has been undermined. But as Nir Eyal outlines, we need to make a distinction between cases where the curtailment of options is a result of the offer itself, and those cases where it is merely the result of (often non-ideal) circumstances, as it is often only the former that appears to undermine the voluntariness of a decision.²⁴ Applied to the case of concern here, it is the difference between giving the child the option of donating an organ or having their sibling murdered, and giving the child the option to donate or not, where the latter will result in their sibling dying from disease. The choice of a saviour sibling not to donate does, of course, have such a serious downside that it would make such a decision unlikely, but this is no different from other scenarios involving medical procedures. The voluntariness of a crash victim's decision to consent to a life-saving leg amputation need not be undermined just because the alternative is horrific (they die).

Our argument then is not to deny that features affiliated with being a saviour sibling might influence a child's likelihood to consent to a donation. This seems undeniably plausible. Our argument is to deny that this makes the saviour sibling case special relative to the Standard Child case by violating their autonomy, because features affiliated with the Standard Child case will influence important future decisions too, and so this fact alone is not enough to support the position that the saviour sibling case is special. We think it is the possible influence of two kinds of features of procreative cases that are relevant here: the influence on future choices exerted by a child's knowledge about (one of the) reasons(s) for their existence, and the influence on future choices exerted by environmental conditions. In the saviour sibling case, the former feature would be the child's knowledge that the reason for their existence is (in part) to provide biological material to save the life of their older sibling, while the latter would be the fact that they have the right genetic profile that makes a donation to their sick sibling possible.

The way such features might influence a saviour sibling's choice to donate are clear enough. But take, for instance, the following uncontroversial example of the Standard Child case: two persons whose reason for having a child is (in part) to have an extra person around to share in their love of music. This child will, first, grow up knowing the reason for their existence is (in part) their parents' wish to share their love of music, and second, be raised in a 'music-dense' environment (their parents are always playing music, discussing it, and putting up band posters around the house). Both these features will surely strongly influence the likelihood of the child's choices regarding nontrivial life options (such as what career they choose to pursue, their choice of a partner, and so on), all in a way that we think is analogous to the influences on the decision of a saviour sibling to donate an organ.

An objector might reply here that two relevant differences remain between the saviour sibling case and Standard Child cases which make any influence over a decision to donate particularly concerning. First, the choice to donate an organ involves physical harm and risks, and

²⁴ Eyal, "Informed Consent."

second, the stakes of the decision are very high. But some examples show that harm and high stakes are often also present in the decisions that features of *Standard Child* cases influence. Regarding harm and risk, a person's choice to earn their living as a musician instead of a more secure career is a choice to undergo psychological stress and anxiety, a person's choice to play football as a hobby over chess is a choice to expose themselves to higher chances of concussion, and so on. And as we have argued, parents' motivation for procreation, and the environment in which the child is raised, often influence the likelihood of these kind of choices.

Now, the stakes involved in a decision to donate are obviously extremely high (do it or my sibling dies). But we cannot underplay here the high stakes of other decisions that often present themselves to children in *Standard Child* cases. We think the best example here is decisions regarding the endorsement of religious (and other comprehensive) beliefs. When parents who share a religious belief decide to have a child they are, in effect (whether they are aware of it or not), putting the child in a position where in the future they will be faced with the following high stakes decision: endorse or remain a follower of a particular religious belief, or no longer share in their family members' conception of the good. The stakes affiliated with this decision need not result from any malice or pressure from parents (there is no threat of disownment), but simply from the fact that a certain distance is unavoidably brought in between persons who do not share the same comprehensive conception. To not be able to fully understand family members' outlook on the world, or appreciate their moral compass, or have deep conversations about what they hold most dear, are all great losses.

Consequently, the decision of parents in the saviour sibling case to put their child in a situation where they will (potentially–see note 5) have to make a decision that involves both harm and extremely high stakes, does not make the parents of saviour siblings unique. In commonplace *Standard Child* cases, both the reason for the child's existence and the environment in which they are raised can also influence the likelihood of a child's choice in decisions with the same features. Such influences are inevitable given the social contexts in which persons make decisions, and so long as parents in these cases do not explicitly pressure their child, and ensure a range of different alternative options is available and known to them, there is no violation of their autonomy.

2. Wrongful Parental Motivations/Instrumentalizing the Saviour Sibling

The creation of saviour siblings might also be thought to be a special case for non-consequentialist reasons. The reason that seems most relevant here is the claim that the creation of a saviour sibling wrongfully treats the child instrumentally. If this were the case, then this would certainly bring in a reason to object to the permissibility of creating saviour siblings.

Worries of this kind are common in the medical and bioethics literature. For instance, Lord Robert Winston—a pioneer in fertility technology—argued that creating a saviour sibling "would be using an unborn child as a commodity."²⁵ We think there is an intuitive force to this objection, and that it would apply to all forms (cord blood, bone marrow, and organ donation) of the saviour sibling case. As such, we disagree with the way Sally Sheldon and Stephen Wilkinson portray the nature of the burden of proof as one where an objector to the practice of saviour siblings "must demonstrate that these [sick] children's deaths are less terrible than the consequences of allowing

²⁵ Quoted in Boyle and Savulescu, "Ethics of Using Preimplantation Genetic Diagnosis to Select a Stem Cell Donor for an Existing Person," 1241.

this particular use of [pre-implantation genetic diagnosis]."²⁶ This agent-neutral outlook misses the deontological concern with instrumentalizing others. The reason we have assumed that the parents would not have otherwise chosen to have another child, is to put the concern with instrumentalization in its strongest terms. However, it is necessary to look more closely at this claim.

A very common reason parents with more than one child give for having had their second child is to ensure that their first child has a sibling—to play with, to have as support when older, to have help taking care of aging parents down the line, etc. We will call this the *Companion* case. If this is correct, then parents in these situations are creating the second child (at least partly) for the benefit of the first. Rarely, if ever, do we encounter moral criticism of such parents. Rather, they are often lauded for taking on some costs (of raising another child) for the benefit of their other child. It is at worst considered morally neutral. The mere fact, then, that in the case of saviour siblings the second child is being created to benefit the first child will not be enough to sustain the claim that saviour siblings are special in this regard. If it is permissible to procreate in order to create a *Companion* to provide the older child with the relatively trivial benefits above, then why would it not also be permissible to procreate in order to provide them with a benefit that is absolutely essential to their life?

It is a perhaps uncomfortable truth that parents rarely procreate purely for the sake of the child. In fact, some philosophers doubt that it is even possible to do so because prior to conception, there is no person for whose sake the parents can act.²⁷ If you ask modern day Western parents why they chose to have children, the reason(s) will usually be one or more of: wanting the personal fulfilment of parenting; wanting to pass on genes; wanting a playmate for existing children; religious obligation; satisfying grandparents; or to be taken care of in old age. This list of reasons is probably not exhaustive, but we think these are the most common ones.²⁸ What is notable is that all these reasons are instrumental. They all 'use' the child to a certain extent as a means to some end like the happiness of siblings or pleasing parents, other family members, God, etc.—none of them have anything to do with the child's own interests. The concern with instrumentalization then does not, at first sight, seem particular to the saviour sibling case.

Of course, the fact that even in *Standard Child* cases of procreation the reasons for procreating are often instrumental does not demonstrate that they are morally permissible reasons. It may be the case that it is *never* permissible to procreate for instrumental reasons and saving an existing child's life is just one of many instrumental reasons parents should not use when deciding to have a child. If so, then saviour siblings are not special, and we can stop here, having proven the case. However, Claudia Mills argues persuasively that although it may seem at first undesirable to be valued for instrumental reasons, this is misleading.²⁹ And while Mills thinks the conditions that make instrumentalization acceptable in cases of procreation will not obtain the case of saviour siblings, we disagree.

Mills argues that in personal relationships we do, and should, desire to be valued at least in some sense instrumentally. She asks us to imagine that we are invited to dinner by a friend. When you inquire as to the reason for the invitation, if your friend replies "I invited you for your

²⁶ Sheldon and Wilkinson, "Should Selecting Saviour Siblings be Banned?" 533.

²⁷ Mills, "Are there Morally Problematic Reasons for Having Children?"; Weinberg, *The Risk of a Lifetime*.

²⁸ In our admittedly unscientific social media polls, no respondent gave any reason other than the ones listed. However, in non-Western cultures there are likely to be additional reasons related to the high infant mortality rate and the need for help on small family farms or earning money to support the family. See also Overall, "Reasons to Have Children – Or Not," 149-51.

²⁹ Mills, "Are there Morally Problematic Reasons for Having Children?"

own sake", you would likely feel somewhat offended. She invited me so that I could benefit from *her* amazing company? What you really want to hear is "I invited you because I enjoy your company. You tell the best jokes and give good advice." Mills thinks it is the selfish, instrumental answer that is gratifying to us, and we actually *want* our friends to value us for (certain kinds of) their own selfish reasons.³⁰

Imagine you are adopting a child. It is commendable to adopt the child for the child's own sake, for humanitarian reasons perhaps. However, adopting a child is not only not undermined by, but is actually *enhanced* by the presence of instrumental selfish reasons. It is the difference between later saying to your child "I adopted you to save you from a life of suffering" and "I adopted you to save you from a life of suffering, but also because I knew you would bring so much joy to my life." The latter is a mutual scenario: "I want you for your own sake, but also for my own. We need each other."

However, it is not the case that any and all instrumental reasons are acceptable. Returning to the dinner invitation, you would not be satisfied by a response such as "I invited you for dinner to convince you to drive me to work every day." Likewise, it is not acceptable to adopt a child to be your live-in housekeeper. How do we determine which instrumental reasons are permissible and which are not?

One reason to object to the second reason for the dinner invitation and not the first is because the good that you are providing in the second case is not unique to you. Anyone could offer your friend a ride, but not just anybody could make him laugh and give him good advice. If you were to find out that all along your 'friend' only continued the relationship due to interchangeable goods you provided—rides to work, help moving, etc.—you would likely feel that you were not in fact really friends at all because part of genuine friendship involves the *reciprocal* exchange of *non-interchangeable* goods. This points to the two criteria for an acceptable instrumental reason—it must not undermine the quality of the relationship itself by instrumentalizing the other for benefits that are non-reciprocal, or for goods that are extrinsic to them.

Non-reciprocity of benefits exists where one party receives goods from the relationship and the other does not. Having a friend help you move, but then not returning the favour when they ask for help six months later, is exploiting a friendship in order to receive a one-sided benefit. But even where the exchange of relationship goods is reciprocal so not one-sided, the relationship is still undermined if one or both parties is engaged in it only for non-interchangeable goods. If you drove your friend to work every week (good for them) and enjoyed their company (good for you), this is reciprocal, but you would likely still feel hurt if you found out that they found your company neutral at best and continued the friendship only for the free ride to work that anyone with a car could have provided them.

Returning to procreation, if parents create a child in order to use her as a housekeeper, treating her just well-enough to avoid the involvement of child protective services, they have instrumentalized her in an impermissible way both because the benefits of the relationship are one-sided (in the parents' favour) and the goods she provides (housekeeping services) are extrinsic to her—after all, anybody could mop the floor.

Some defenders of the practice of creating saviour siblings think that while it makes the instrumental nature of reproduction more obvious, it is no less justified than other instrumental justifications for procreation.³¹ Is this right, or does creating a saviour sibling constitute a special

³⁰ Mills, "Are there Morally Problematic Reasons for Having Children?" 4.

³¹ Robertson et al., "Conception to Obtain Hematopoietic Stem Cells," 36.

case of wrongful instrumentalization? Mills thinks it might. First, she thinks that while there are plenty of instrumental reasons for having children that create reciprocal benefits, she doubts that saviour siblings create reciprocal benefits. If parents decide to have a second child so that their first child can have a companion and lifelong support, the benefit there is reciprocal because both siblings are benefiting the other in the same way. By contrast, Mills doubts that there is a reciprocal exchange of benefits in the saviour sibling case because the proposed benefit (life of the sick child) is one-sided. The saviour sibling is intended as a donor for the existing child, but not vice versa.³² We are not so sure.

First, note that even if Mills is right that there is no reciprocal exchange of benefits in the saviour sibling case, there is not necessarily a reciprocal exchange of benefits in *Standard Child* cases either. The most likely case for a reciprocal exchange of benefits is probably the *Companion* example. Imagine that the older child loves their sibling, but the younger child strongly dislikes their sibling and as they grow older, they become estranged. This would not be particularly unusual; after all, you do not choose your family! In this case there is no reciprocal exchange of benefits so perhaps the parents having the second child to be a companion for the first was impermissible. But this seems to peg the permissibility of the reproductive act on the outcome, not on the parents' motivations which were honourable—to create reciprocal benefits for both children. This seems wrong since what non-consequentialists find impermissible about instrumentalizing people is not what ultimately happens to them, but about how you relate to them—i.e., one's motivations/reasons for acting, not outcomes. A non-reciprocal exchange of benefits outcome can result from any of the instrumental reasons for procreation, saviour siblings included. Perhaps all of these motivations for procreation are wrongful if they have the undesired result, but saviour siblings are not special in this regard.

Second, it is not necessarily true that there is no potential reciprocal benefit in the saviour sibling case. When the saviour sibling is created, they become part of the family. They give the benefit of life to the sick child, but they also receive benefits in return. Many philosophers see existence itself as a benefit, but even for those who don't, there are other benefits for the saviour child like their sibling's companionship and their parents' love. What counts in determining reciprocal exchanges is not direct equivalence of benefits; reciprocity need not be a tit for tat exchange. As Lawrence C. Becker notes, perfect returns in-kind would often defeat the purpose of the reciprocity in the first place: "I don't want a popcorn popper, that is why I gave you mine." According to Becker, and we find his account convincing, what counts is that the return is both fitting and proportionate. The benefits affiliated with cases like *Companion* seem to satisfy these two conditions, but we do not see why the benefits associated with the saviour sibling case cannot satisfy them too.

The expected benefits for the saviour sibling can be regarded as a fitting response to the benefits received by the older child, given both are connected to the welfare of persons and their ability to be involved in loving relationships. It is a return that is of the right kind, in a way that giving the saviour sibling a million dollars and then putting them up for adoption would not be.

But what about proportionality? This might be what motivates someone who finds the saviour sibling case problematic, given that the act of saving a life clearly only goes one way. It might be true that no level of benefits received by the saviour sibling could ever be commensurate to the benefit they gave to their older sibling. But this does not mean the proportionality condition

³² Mills, "Are there Morally Problematic Reasons for Having Children?" 6.

³³ Becker, *Reciprocity*, 107-8.

³⁴ Becker, *Reciprocity*, 106ff.

of reciprocity is violated, as often proportionality in terms of costs or effort seems just as appropriate as proportionality of benefit. For example, imagine your neighbour returns your dog that went missing. You surely are not in their debt until you rescue *their* dog. If, say, your neighbour 'found' your dog simply because it walked into their yard while they were enjoying a picnic, a thank you seems proportionate. If, however they found your dog after joining you on a citywide search all night, then a bigger gesture of thanks seems called for. A saviour child, despite giving a great benefit to their sibling, has not put an inordinate amount of effort (and in the cord blood case they have not put any effort) into creating those benefits (arguably, the effort is made by the mother through pregnancy). So, even if a saviour sibling could never receive a benefit that is strictly commensurate with the benefit they gave to their older sibling, this does not exclude the possibility of a reciprocal relation. The saviour sibling case then, is not a special case of instrumentalization from non-reciprocity or one-sided benefits.

Of course, were the parents to take the biological material from the child, then shut them away for eighteen years giving them only the minimum required for life, then they would not enjoy any reciprocal benefits, and this would be wrongful instrumentalization. But we could concoct similar forms of treatment in relation to all of the other possible ways parents decide to have children for instrumental reasons in *Standard Child* cases. What counts is that a child conceived for instrumental reasons (which, remember, is likely almost all children) can plausibly expect a reciprocal return of benefit, and in the saviour sibling case they can. And, as noted earlier, it borders on absurd to think that parents who love their first child so much that they would consider going through IVF, embryo selection, and pregnancy in order to save their life, could be the same parents who would treat the child that saved the first child so callously that the child would receive no reciprocal benefits from their creation.

However, Mills also thinks that the saviour sibling case might be a wrongful form of instrumentalization due to the benefits involved being *external* to the relationship itself. Creating someone for their particular genetic profile is not instrumentally valuing them for their unique contribution to the relationship, the argument goes, but valuing them for something which anyone could provide (like valuing a friendship only for the free car rides to work). As Mills recognizes, the puzzling point here is that in deciding to procreate, even in *Standard Child* cases, *no* parent can value their child for themselves, given they know not a single thing about them.³⁵ As such, when one decides to procreate for instrumental reasons there will always be *some* acknowledgement of the interchangeability of goods, given it is expected that any child of the set of possible children will be able to provide the benefit. Consequently, the fact that the benefit received from the donation of a particular genetic profile is interchangeable (anyone with the right profile could in theory provide it) does not make the saviour sibling case different from other cases of procreation for instrumental reasons.

However, what Mills thinks *does* bring in a relevant difference between the saviour sibling case and acceptable forms of instrumental procreation, is that the goods provided in the saviour sibling case are not intrinsic to the parent-child relationship.³⁶ In *Companion*, the benefit received (life-long support and love between two siblings) is something which can only be provided by having another child. But if one, say, decided to have a child only for the security of being cared for in old age, the benefit received is not unique to the relationship (it need not be a child that takes care of you when you are elderly).

³⁵ Mills, "Are there Morally Problematic Reasons for Having Children?" 8.

³⁶ Mills, "Are there Morally Problematic Reasons for Having Children?" 9.

Our reply here is twofold. First, in the case being considered here—parents of children with leukemia and anaemia—saviour siblings often *are* the only persons who can provide such a benefit. If alternative donors were available, the saviour sibling would not be needed. As such, the benefit *is* unique to the parent-child relationship. Second, the motivations for choosing to have a saviour sibling *themselves* originate from a parent-child relationship. It is out of a concern to not have their other child die that the parents decide to have a saviour sibling. And so, while the child might be created for instrumental reasons, they are not created for reasons inimical or opposed to valuable relations between a parent and their child—it is because the parent loves their child unconditionally that they decide to have another child. Of course, if the parents put the saviour sibling up for adoption immediately following donation, then this would express that they were only valued instrumentally for something external to an appropriate parent-child relationship (let alone be an unacceptable way to treat a child). But again, the saviour sibling case is not special in this regard. We would say the same thing if in *Companion* the child is put up for adoption once it becomes obvious the sibling relationship is not working out.

These comments show that saviour siblings do not present a special form of instrumentalization because they can expect reciprocal return of benefits, and that because there are no other options of donation available and because the motivation for their creation is internal to a parental-child relationship, they are not being valued merely for providing benefits that are interchangeable. We think what is really driving the instrumentalization objection is a worry that the child will be mistreated somehow, that parents will not relate to their child in the right way. But again, rather than being an argument that saviour siblings *per se* present a special case, this points to the important factor being not the reasons for the child's conception but their treatment after birth. No one worries about the children created to be *Companions*, nor the children created for the array of other instrumental reasons that make up the *Standard Child* case. Why do we worry about saviour siblings?³⁷

3. Conclusions

There is clearly something different about saviour siblings compared to other children—they are created to save another. Our claim in this paper has been that this descriptive difference does not raise special normative issues of procreative (im)permissibility. On the contrary, the conditions in which it is (im)permissible to create a saviour sibling are the same conditions in which it is (im)permissible to create any child.

We first argued that there is either nothing inherent to the creation of saviour siblings that will lead to physical harm (cord blood case), or if there is physical harm (bone marrow or organ donation case) then the procedure would only ever be permissible if the same ethical and legal requirements which exist in *Standard Child* cases are met. Furthermore, given bone marrow and

³⁷ One might argue that there is something else special about saviour siblings—viz. that they are genetically selected for the benefit of a third party. For this objection to hold, it must be the case that saviour siblings are special compared to the Standard Child just in case they are genetically selected to help a third party in a way that a Standard Child is not. We have already argued that creating a child to benefit a third party is not necessarily impermissible, so it must be the fact that the child was genetically selected that is relevant. This takes us into a more general bioethical debate about the permissibility of genetic selection itself. If genetic selection for anything other than disease prevention is impermissible, then saviour siblings likely are too, but not because they are saviour siblings. Thank you to an anonymous reviewer for suggesting this objection.

organ donation are only possible and not inevitable outcomes, the saviour sibling case is no different to all those instances of the *Standard Child* case where parents are choosing to create a child in the knowledge that they may be harmed and/or experience pain in the future. We then argued that saviour siblings are no different to *Standard Child* cases of procreation when it comes to the possibility of the child experiencing psychological harm, whether this results from either their knowledge of the reason for their existence, or from the treatment they receive from their parents.

We also argued that a child's autonomy is no more undermined in the saviour sibling case than in the *Standard Child* case. It is of course true that saviour siblings do not consent to being born for the purpose of donation, nor to undergoing medical treatment at a stage of precompetence. But this does not make saviour siblings special because no child consents to being born for any purpose and parents make decisions about their pre-competent children's medical treatment all the time. And while it might be thought being created for the purpose of blood donation undermines the child's right to an 'open future' by making them more likely to make further donations later in their life, or that any choice to donate an organ by a saviour sibling can never be a case of 'informed consent,' this either results from an erroneous conflation of increased likelihood to donate with involuntariness, or from unacceptable pressuring from parents. And the latter is a behaviour that will also violate the autonomy of children in *Standard Child* cases.

As we outlined, the reasons driving most (all?) procreation are instrumental. And this instrumentalization need not make reasons for procreation wrongful but can actually be a good thing, so long as the benefits involved are reciprocal and non-interchangeable. And we argued that there is nothing stopping the instrumental reasons underpinning the saviour sibling case meeting these two conditions. What seems to be driving concerns about instrumentalizing saviour siblings is a worry that the child will be mistreated somehow. A child being mistreated would of course be terrible, but it would be terrible because the child was mistreated, not because they were instrumentalized. In fact, if it were possible to create children for their own benefit (though as we said, many doubt this), it would be no less terrible for the child who is born for this reason to be mistreated than for a child who is created for some instrumental purpose that is acceptable (like a saviour sibling).

What the argument highlights is that any wrong-making features in the creation of saviour siblings are no different from those in *Standard Child* cases, in particular the quality of the child's life (including how they are treated and related to) once they exist. In other words, what would make having created a saviour sibling wrong would be no different from what would make having created a 'standard' child wrong—neglect, abuse, lack of love, lack of respect for autonomy, etc.³⁸

However, although we have argued that the unique reason for their birth does not affect the moral permissibility of creating them, this special feature of saviour siblings might have normative implications about whether their creation may actually be morally obligatory. In the case being considered here (no other available donors), creating a saviour sibling is the only option to prevent a significant bad from happening (a child dying). As such, an answer as to whether the practice is morally obligatory will need to be sensitive to how we weigh the prevention of such a bad against the costs imposed by the practice on parents (especially mothers). These are clearly both morally weighty reasons, and it is not immediately obvious how such a weighting would best be made.

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³⁸ Spelling out exactly what children are entitled to expect from their parents on pains of having been wronged is beyond the scope of this paper, but promising accounts can be found in Liao *The Right to be* Loved, and Magnusson, "Children's Rights and the Non-Identity Problem."

Unfortunately, examining the implications of this special feature of saviour siblings must be a task left for future work.³⁹

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References

- Beauchamp, Tom L. and James F. Childress. *Principles of Biomedical Ethics*. 6th ed. Oxford: Oxford University Press, 2008.
- Becker, Lawrence C. Reciprocity. Chicago: University of Chicago Press, 1990.
- Benatar, David. *Better Never to Have Been: The Harm of Coming into Existence*. Oxford: Oxford University Press, 2006.
- Bizzetto, Renata et al. "Outcomes After Related and Unrelated Umbilical Cord Blood Transplantation for Hereditary Bone Marrow Failure Syndromes other than Fanconi Anemia." *Haematologica* 96, no. 1 (January 2011): 134-41.
- Boyle, Robert J. and Julian Savulescu. "Ethics of Using Preimplantation Genetic Diagnosis to Select a Stem Cell Donor for an Existing Person." *British Medical Journal* 323, no. 7323 (November 2001): 1240-43.
- Brierley, Joe and Vic Larcher. "Organ Donation from Children: Time for Legal, Ethical and Cultural Change." *Acta Paediatrica* 100, no. 9 (September 2011): 1175-79.
- Campbell, M., L. Wright, R.A. Greenberg, and D. Grant. "How Young is Too Young to be a Living Donor?" *American Journal of Transplantation* 13, no. S4 (July 2013): 1643-49.
- Chan, Tak Kwong and George Lim Tipoe. "The Policy Statement of the American Academy of Pediatrics Children as Hematopoietic Stem Cell Donors A Proposal of Modifications for Application in the UK." *BMC Medical Ethics* 14, no. 1 (October 2013).
- Clayton, Matthew. "The Case against the Comprehensive Enrolment of Children." *The Journal of Political Philosophy* 20, no. 3 (September 2012): 353-64.
- Dillon, Robin S. "Self-respect and Self-Esteem." In *International Encyclopaedia of Ethics*, edited by Hugh LaFollette. Wiley Online Library, 2019. https://doi.org/10.1002/9781444367072.wbiee221.pub2

³⁹ The authors share equal responsibility for this article. An earlier version of this paper was presented at the 2022 Bucharest Conference in Analytical Political Theory, and we would like to thank participants for their helpful questions and discussion. We would also like to thank the two external reviewers for their detailed comments which led to an improved paper.

- Dworkin, Gerald. *The Theory and Practice of Autonomy*. Cambridge: Cambridge University Press, 1988.
- Dworkin, Ronald. "The Original Position." In *Reading Rawls: Critical Studies on Rawls' 'A Theory of Justice*, 'edited by Norman Daniels, 16-53. New York: Basic Books, 1975.
- Enoch, David. "Hypothetical Consent and the Value(s) of Autonomy." *Ethics* 128, no. 1 (October 2017): 6-36.
- Eyal, Nir. "Informed Consent." In *The Stanford Encyclopedia of Philosophy*, edited by Edward N. Zalta. Spring 2019 Edition. Available at: https://plato.stanford.edu/archives/spr2019/entries/informed-consent/
- Feinberg, Joel. "The Child's Right to an Open Future." In *Freedom and Fulfillment: Philosophical Essays*, 76-97. Princeton: Princeton University Press, 1992.
- Hannan, Sarah. "Childhood and Autonomy." In *The Routledge Handbook of the Philosophy of Childhood and Children*, edited by Anca Gheaus, Gideon Calder, and Jurgen De Wispelaere, 112-22. New York: Routledge, 2018.
- Haude, K., P. McCarthy Veach, B. Leroy, and H. Zierhut. "Factors Influencing the Decision-Making Process and Long-Term Interpersonal Outcomes for Parents Who Undergo Preimplantation Genetic Diagnosis for Fanconi Anemia: A Qualitative Investigation." *Journal of Genetic Counseling* 26, no. 3 (June 2017): 640-55.
- Kakourou, Georgia, Christina Vrettou, Maria Moutafi, and Joanne Traeger-Synodinos. "Pre-Implantation HLA Matching: The Production of a Saviour Child." *Best Practice & Research Clinical Obstetrics & Gynaecology* 44 (October 2017): 76-89.
- Leung Wing et al. "High Success Rate of Hematopoietic Cell Transplantation Regardless of Donor Source in Children with Very High-Risk Leukemia." *Blood* 118, no. 2 (July 2011): 223–30.
- Liao, S. Matthew. *The Right to Be Loved*. New York: Oxford University Press, 2015.
- Locatelli, Franco. "Outcome of Patients with Hemoglobinopathies Given either Cord Blood or Bone Marrow Transplantation from an HLA-Identical Sibling." *Blood* 122, no. 6 (August 2013): 1072-78.
- Magnusson, Erik. "Children's Rights and the Non-Identity Problem." *Canadian Journal of Philosophy* 49, no. 5 (August 2019): 580-605.
- Mills, Claudia. "Are there Morally Problematic Reasons for Having Children?" *Philosophy and Public Policy Quarterly* 25, no. 4 (Fall 2005): 2-9.

- Mullin, Amy. "Children, Autonomy, and Care." *Journal of Social Philosophy* 38, no. 4 (Winter 2007): 536-53.
- Overall, Christine. "Reasons to Have Children Or Not." In *The Routledge Handbook of the Philosophy of Childhood and Children*, edited by Anca Gheaus, Gideon Calder, and Jurgen De Wispelaere, 147-57. London: Routledge, 2018.
- Radcliffe Richards, Janet. "A World of Transferable Parts." In *A Companion to Bioethics*. 2nd ed., edited by Helga Kuhse and Peter Singer, 375-89. Chichester: Wiley-Blackwell, 2009.
- Robertson, John A., Jeffrey P. Kahn, and John E. Wagner. "Conception to Obtain Hematopoietic Stem Cells." *Hastings Center Report* 32, no. 3 (March-April 2002): 34-40.
- Rocha, Vanderson et al. "Graft-Versus-Host Disease in Children Who Have Received a Cordblood or Bone Marrow Transplant From an HLA-Identical Sibling." *The New England Journal of Medicine* 342, no. 25 (June 2000): 1846-54.
- Ross, Lainie Friedman et al. "Children as Hematopoietic Stem Cell Donors." *Pediatrics* 125, no. 2 (February 2010): 392-404.
- Rubeis, Giovanni and Florian Steger. "Saving Whom? The Ethical Challenges of Harvesting Tissue from Savior Siblings." *European Journal of Haematology* 103, no. 5 (November 2019): 478-82.
- Sachs, David. "How to Distinguish Self-Respect from Self-Esteem." *Philosophy & Public Affairs* 10, no. 4 (Fall 1981): 346-60.
- Saunders, Ben. "Consent and Organ Donation." In *The Routledge Handbook of the Ethics of Consent*, edited by Peter Schaber and Andreas Müller, 311-21. London: Routledge, 2018.
- Sheldon, Sally and Sheldon Wilkinson. "Should Selecting Saviour Siblings be Banned?" *Journal of Medical Ethics* 30, no. 6 (December 2004): 533-37.
- Strong, Kimberly et al. "It's Time to Reframe the Savior Sibling Debate." *AJOB Primary Research* 2, no. 3 (October 2011): 13-25.
- Weinberg, Rivka. *The Risk of a Lifetime: How, When, and Why Procreation May be Permissible*. Oxford: Oxford University Press, 2016.
- Wilkinson, T. M. Ethics and the Acquisition of Organs. Oxford: Oxford University Press, 2011.
- Wolf, Susan M., Jeffrey P. Kahn, and John E. Wagner. "Using Preimplantation Genetic Diagnosis to Create a Stem Cell Donor: Issues, Guidelines and Limits." *Journal of Law, Medicine, and Ethics* 31, no. 3 (Fall 2003): 327-39.