

Editorial

Saviors as saints or sinners?

Advances in medical science are frequently characterized by two related phenomena. First, they create the opportunity for individuals to make choices previously unavailable and thereby pose new moral questions that challenge both our moral intuitions and social institutions. Second, innovation in healthcare unfolds, both in the sense that its utilization spreads geographically but also that it triggers further innovation in science and in practice. A new kind of prenatal diagnosis is a recent example. Preimplantation genetic diagnosis allows parents to select and bear a child whose genetic make-up can help a sibling survive a chronic or life-threatening health problem. The growing incidence of nurturing what have been called “savior siblings” offers an occasion for moral reflection while, at the same time, is a vivid example of repeating patterns of progress in medicine.

This brief comment will focus on moral issues, but a passing reference to the pattern of scientific progress will be helpful, if only to remind us that further developments in reproductive science and therapeutics will render some of the moral quandaries otiose. Breeding and bearing genetically selected donors would not be possible were it not for our ability to fertilize ova *in vitro*, to identify the genetic make-up of embryos, and to successfully implant the embryos chosen. Each element prompted moral debate when it was introduced. Our future ability to genetically engineer gametes and embryos and to rear them in artificial environments will eliminate some of the current ethical concerns but, of course, raise others. The current focus of the moral conversation is the creation of savior siblings and to that I turn.

Couples have children for all sorts of reasons – some laudable and others questionable – and some have children for no reason at all. Wanting to have a child to benefit another child – if only as a companion – is rather common. Furthermore, people have often wished to and have sought to influence, if not determine, the characteristics of their offspring. Sometimes this

involves prenatal testing and terminating a pregnancy when the fetus is found to carry some unwanted genetic condition. What has raised eyebrows is parents choosing to bear children with the avowed intention of ameliorating or even eliminating a genetic condition or other illness of a living sibling.

How might we think about this issue? What are the values involved? Whose and which values should have priority when, as is the case here, they do not all line up? Before addressing questions about nurturing a savior sibling, we must recognize that some people believe we should not **think** about them at all. They believe that moral quandaries like this one are best addressed by an appeal to moral intuitions or instincts rather than rational thought (1). On this view the practice of creating savior siblings violates such basic ethical values, is so abhorrent that the exercise of balancing benefits and burdens or looking at rights and duties is entirely misdirected. Nurturing savior siblings – like cannibalism or mother/son incest – is simply revolting and reasoning about it beside the point. Especially odious activities have a “Yuk Factor” to which our moral intuitions respond.

The problem with this view is that there is seldom agreement across cultures or over time on what qualifies as Yukkie. Those of you who believe that creating savior siblings is a revolting idea and either unworthy of or not amenable to moral argument should stop reading and skip to the end.

Likewise, if you believe that IVF itself is immoral, you may skip to the end. Given our current technology, producing savior siblings with reasonable probability of success involves IVF. There are, of course, various reasons one might have for questioning the morality of IVF. I mention two but do not scrutinize them here. Some object to IVF because it is a presumptuous use of our scientific abilities and involves an excursion into realms best left to God. Others question the procedures for handling unused

embryos – currently(!) by transfer to a uterus, perpetual storage, use in research, or disposal. If one attaches significant moral standing to these early embryos, all but the first of these options is morally unattractive.

Finally, if you believe that prenatal diagnosis is itself immoral, you may skip to the end. At this point few will drop out absent two further specifications. First, what is the response to negative information gained prenatally? Is the gestation terminated, the genetic trait modified, or some other accommodation made for the condition of the offspring. The first of these options would be opposed by many of the advocates of sanctity of life, though some of those would say disposing of preimplantation genetic diagnosis embryos is morally preferable – less evil – than terminating a pregnancy (2). Second, what sorts of conditions are looked for and/or selected. Here we come to the moral difference, if any, that arises between positive and negative eugenics. Selection to avoid devastating genetic conditions draws little opposition. Selection for traits thought socially advantageous to the prospective child – gender, strength, intelligence, beauty – is far less acceptable. The concept of creating savior children is unusual because, though the selection is for an advantageous trait, the advantage is designed to benefit not the prospective child, but another child already in being.

We can now focus on the moral question facing those considering having or helping others to have a savior sibling. Is it morally permissible to use preimplantation genetic diagnosis to select and nurture a baby to help address a health condition – e.g., leukemia or a potentially lethal anemia – of an extant sibling?

First, most of us would ask what are the benefits and harms that the practice produces and, also important, on whom do the benefits and burdens fall. The former raises the classic questions of consequentialist moral reasoning; the latter, issues of justice.

A dominant approach to medical ethics requires that one determine the moral “valence” of all of the consequences of an action on everyone for all time. More practically, consequentialists want to determine who are the parties likely to be most affected by the action and what is the probable impact on them. The affected parties in the evaluation of savior siblings are the savior, the sibling(s), the parent(s), the healthcare providers and, more distantly, the society. I believe that the balance is *prima facie* in favor of the procedure, but it is too soon to have a great deal of confidence in the

data. Families and children are being followed, and to date the evidence is encouraging.

The recipient sibling is the most obvious likely beneficiary of a successful procedure. Whatever the triggering condition – Fanconi anemia, Diamond-Blackfan anemia, Hyper IgM syndrome, beta-thalassemia major, to mention examples that have been reported in the press – the donation is designed to and can eliminate or moderate the condition. The psychological impact of being saved by a sibling is being studied and firm conclusions cannot yet be drawn from the scant data.

The mother donating the eggs bears the burden of the onerous IVF process, but does so by choice. It is fair to assume that she does so because she believes the burdens – physical, psychological, economic, spiritual – are outweighed by the benefits of saving her sick child, of relieving burdens on her family, and of having an additional, healthy child. No mother has ever admitted having a savior sibling for the first reason alone.

Healthcare providers who participate in this procedure are affected by its outcome. They are surely proud and gratified when it succeeds. They run few, if any, direct risks though would appropriately feel sadness and disappointment were the procedure to fail.

The donor or savior sibling seems, at first blush, to be the only party in whom the burdens might outweigh the benefits. Granted they are “selected” because of their potential to help their sibling, but are also more likely than the average newborn to be free of discoverable genetic disease. There is no evidence that they are less valued than other children in the family and one could imagine them being more valued. There are no reports that savior children are wanted or valued **only** because of their role as rescuers. If the need for donation repeats or continues over time, the burden of donating itself becomes more onerous and the assent or consent of the savior will eventually be necessary. And as in Jodi Picoult’s *My Sister’s Keeper*, that consent may not be forthcoming. Again the psychological impact of being conceived to save a family member remains an open question.

Before turning to the wider societal issues, it must be noted that cultures that place extraordinary value on individualism – as in the United States – will find creating savior siblings more troubling than cultures in which familial and communal responsibilities are valued more highly. The odd thing about American culture is that we often ignore the fact that all of us individuals are born into and raised by families

which give meaning to who we are as individuals. There is an irony when we rely on individualistic autonomy to attenuate the claims of that empowering family. To expect some sacrifice by one member of a family for the benefit of others is common place and morally appropriate.

What of societal concerns? Should IVF and preimplantation genetic diagnosis to produce savior siblings be covered by insurance? Public insurance? Will having some disabled children saved by their siblings have implications for our attitude toward other disabled children from families for whom cost or other conditions prevented access? Here issues of justice enter into the analysis. So long as there are children with no health insurance at all and pregnant women with no access to prenatal care, I find these questions about economic support for preimplantation genetic diagnosis premature at best. The ability to produce savior siblings might be a kind of transitional technology that addresses a need that will in the future be met more efficiently by other scientific advances. Yes, the procedure is on balance a blessing. However, with the huge moral issues facing our healthcare delivery system, we ought not get captivated by savior siblings and thereby distracted from the more important moral problems in healthcare facing us.

Finally, there are the issues arising from moral concerns that look at other than consequences. What of the donor's autonomy? Are we not violating Kant's imperative that we never use someone as a means alone for another's benefit? Alternatively, would not interfering with a

family's decision to try these procedures be an invasion of familial privacy?

These are appropriate questions and some, easy to answer. The fact that deciding to have a child typically results from a mixture of motivations in no way precludes the actual child being valued as an end in herself. Savior children are typically valued in their own right and are not used as a means alone. Parents of necessity choose for children; autonomy develops with moral capacity. Familial privacy is not an absolute value.

Selecting and nurturing savior siblings does raise important issues of direct relevance to some parents and healthcare providers. Cataloguing and resolving the issues is an exercise of moral judgment and reasoning that most of us do, I suggest, successfully. The bigger challenge is just around the corner and will arise vividly when we perfect our ability to engineer genes.

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