

Should Parents of Neonates With Bleak Prognosis Be Encouraged to Opt for Another Child With Better Odds? On the Notion of Moral Replaceability

Torbjörn Tännsjö, Professor Emeritus of Practical Philosophy

abstract The notion of moral exchangeability is scrutinized and its proper place in neonatal care is examined. On influential moral outlooks, the neonate is morally exchangeable. On these views, if the parents are prepared to let go of the neonate with a poor prognosis and opt instead for another child who is healthy, this may be the morally right thing for them to do, and neonatal care ought to ease their choice.

The notion of moral exchangeability has a different place in different moral theories. Three theories are examined: deontological ethics (insisting on the sanctity of innocent human life), according to which there is no place for the replacement of 1 child for another. It is different, however, with utilitarianism and in the moral rights theory based on self-ownership. According to utilitarianism, we are all replaceable. According to the moral rights theory, neonates are replaceable to the extent that they have not developed personhood. Even a deontological ethicist of a Kantian bent would concur here with the moral rights theory.

Because influential moral theories imply that the neonate is morally exchangeable, it is reasonable within neonatal care, as a general rule, to grant the parents a veto against any attempts to save a child with a poor prognosis. In particular, if the parents are prepared instead to have another, healthy child, this is to be recommended. However, this rule cannot be strict. In rare cases, it is necessary to yield to parents who insist that their neonate be saved despite a poor prognosis.

Department of Philosophy, Stockholm University, Stockholm, Sweden

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Address correspondence to Torbjörn Tännsjö, Department of Philosophy, Stockholm University, 106 91 Stockholm, Sweden. E-mail: torbjorn.tannsj@philosophy.su.se

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A child is delivered at 23 weeks' gestation with several complications. The doctors believe there are some chances that the life of the child can be saved with acceptable quality but only after massive medical and surgical interventions. They believe also that the child might die regardless of their attempts to save it. Finally, they concede that there is a possibility that they can save the child but to a life that is a burden on both the child itself and its parents. In this situation, at least 2 questions are posed to us who reflect on it. First of all, given the possible outcomes, ought the doctors try to save the child? Secondly, who should make the decision about this?

I will discuss the case from the point of view of my own specialty, which is moral philosophy, and I will focus on the notion of moral replaceability.

MORAL PHILOSOPHY AND MEDICAL PRACTICE

Could moral philosophy make a difference in medical practice? In some cases, I will argue yes. This is in regard to decisions that are made at the beginning and at the end of our lives.

The issues that surround euthanasia and abortion are highly sensitive. Here, it is often impossible to reach common practical conclusions about concrete cases. Conflicts abound. And the conflicts depend crucially on the different philosophical points of departure. We face fundamental moral disagreements. Here, the case we are considering gives rise to similar moral concerns. People who agree about all the relevant nonmoral facts may reasonably disagree about what should be done. Their disagreement can be traced back to their different moral points of departure. In their reasoning, they rely on different and mutually inconsistent moral principles.

THE MEDICAL BACKGROUND

In the example I gave, additional medical questions arise. The example has been described in an unreasonably abstract manner. Here, the medical doctor is supposed to fill out the medical details. I noted that the child was born at 23 weeks' gestation. This means that the child was extremely premature. And yet, there are several examples in which children who were born at 23 weeks' gestation have survived. As a matter of fact, some 50% of them do. Could this be an example? I have assumed that the answer to this question is perhaps. I also added that the child would only survive if advanced medical and surgical measures were undertaken. If we place ourselves in the position of the parents, there are lots of additional information that we want to have from the doctor. How painful will the treatment of the child be? How likely is it that the child will survive? How likely is it that the child will survive but have a life that is not worth living?

It is not unusual that doctors hesitate to provide the information they have. The reason is sometimes based on misunderstanding. The doctors may say that they have access to statistical information about similar cases, but such information has nothing to say about this individual case at hand. I have even received the answer that there is no such thing as probabilities in individual cases (from a doctor who treated me). But of course, there is. It is true that these probabilities are subjective. Yet, they exist, and they provide the only possible basis for a reasonable decision.

Suppose we manage to convince the doctor to reveal how he or she assesses the case at hand. Let us suppose we now end up with the following report:

there is a 10% probability that we save the infant to a life worth living;

there is a 45% probability that the life of the infant will not be saved regardless of the attempts we make to save it; and

there is a 45% probability that the life of the infant is saved but that it is saved to a life that will be a burden on both the child and the parents.

Let us also assume that the doctor judges that the suffering of the child will be severe although attempts are being made to save the child's life.

Given this simplified description of the medical facts, it is possible for people who adhere to different moral principles to reach conflicting verdicts about whether the infant should be saved.

MORAL PHILOSOPHY: 3 NORMATIVE THEORIES

In my discussion about the case, I take my point of departure from 3 different moral principles. I will speak on the following:

the sanctity-of-life doctrine;

the moral rights theory, which is based on self-ownership; and
utilitarianism.

In my book *Taking Life: Three Theories on the Ethics of Killing*,¹ I present these theories in depth and discuss at length their implications for different kinds of killing (such as suicide, euthanasia, and abortion). Here, I will apply them to the context of neonatal care.

I focus on these 3 theories because they each have competent and contemporary advocates, they yield definite verdicts in cases such as the one at hand, and, they yield conflicting verdicts.

The sanctity-of-life doctrine is a deontological view. This means that there are types of actions (the example of interest here is, of course, killing) in which regardless of the consequences in an individual case, instances of them are wrong,

period. It is further claimed that we reasonable people can understand that this is so.

The particular form of deontology that I am referring to here has its roots in the Thomas Aquinas thinking. In its up-to-date version, it is held by the Pope but also by many adherents of the other monotheistic religions. It is not religious in nature, however. Its criterion of wrong actions makes no essential reference to God. Here is how it delineates a class of absolutely morally forbidden actions: it is wrong to intentionally kill an innocent human being.

Only the innocent human life is protected by this doctrine. This doctrine is compatible with capital punishment. I leave that aside in the present context.

A question that is crucial to the understanding of this doctrine is when human life begins. The standard answer to this metaphysical question is at conception. This means that whereas I have been an embryo, a fetus, a neonate, and so forth, I have never been a sperm or an egg. The egg and the sperm were materials from which I was created. Once the fertilized egg existed with its unique genome, I came into existence.

The metaphysical foundation of this doctrine makes fairly good sense. Furthermore, given this foundation, it is clear that a neonate who is born at 23 weeks' gestation is a human being. It is also hard to come up with any reason as to why this infant should not be innocent. Hence, according to this doctrine, it would be wrong to kill this infant.

Could it be acceptable to allow the infant to die? No, the distinction between acts and omissions plays no role in this theory. According to this view, to stop providing life-sustaining treatment, means intentionally killing the infant, and this is prohibited. If you follow the advice from the sanctity-of-life doctrine when applied to the case at hand, you go to all

lengths in your attempts to save the infant.

Could this infant be seen as replaceable? Would it make sense to allow the child to die and then hopefully conceive another child who is healthy in its stead? Clearly not. The child is a unique individual. It is not replaceable. From the point of view of the sanctity-of-life doctrine, no innocent human being is replaceable.

The moral rights theory, which is based on the notion of self-ownership, has its source in the English philosopher John Locke (1632–1704); in modern times, it has been advocated for by the American philosopher Robert Nozick (1938–2002). Its point of departure is that we “own” ourselves in a moral sense of the word. This means that we have a right to do as we see fit with ourselves unless by doing so, we violate the equal right of anyone else. We do so if we actively kill a person, put a knife in his or her abdomen, or even touch him or her without consent. However, with a person's consent, we are allowed to do all these things. Neither assisted death nor suicide is a moral problem when assessed from the point of view of this theory of moral rights.

Who possesses this self-ownership? If we want to understand the theory here, we have to answer another metaphysical question. According to this theory, it is neither necessary nor sufficient to be a human being to possess rights. The crucial thing is that you are a person (a moral subject). It is not crystal clear what this means, but the general idea is that those who possess rights should also be capable of respecting rights. To be a moral subject (a person), you must at least possess an idea of yourself as an entity who exists over time with a past, present, and future.

When does a human individual acquire the relevant kind of self-consciousness? This is a moot

question, and moral rights theorists tend to disagree. However, it is clear that an infant who is born at 23 weeks' gestation does not possess the necessary characteristics. It doesn't possess any rights.

The fact that it doesn't possess rights means that from the point of view of the moral rights theory, it is replaceable. It is all right to kill it. However, it is not all right to harm it in a manner meaning that later on, if it survives, it suffers from what was done to it before it became a person. It is not wrong to kill a fetus or a child who is just born at 23 weeks' gestation, but it is wrong to treat it in a manner to which it will complain when the time comes for it to assess what you did.

What about a situation in which you create or allow a fetus to develop into a person with a life that is not worth living? Then you have wronged this child.

What would the adherents of this view say about our example? They would say that our child in the example is not a person. It has no moral rights. Hence, no obligation exists to try to save its life. Moreover, if the child is saved but to a life that is not worth living, then this action is wrong. Of course, if the child is saved to a life that is worth living, then it has not been wronged. But note that when, ignorant of the outcome, you save it, you run a moral risk. Your action can turn out to be wrong. If you do not make the attempt, no moral problem exists. A merely potential person cannot raise any complaint.

On this view, because the infant is not a person, it is replaceable. It might therefore be a good idea for the couple to allow the child to die and make a new attempt in which the (moral) odds are better.

In utilitarianism, we are urged to maximize the sum total of happiness in the universe. If an action maximizes the sum total of

happiness in the universe, it is right. If it doesn't, it is wrong. I am myself a utilitarian and so is Peter Singer to name 1 famous adherent of the theory.

Clearly, utilitarianism is a highly demanding theory. It is demanding because if you want to follow it, you must go to great lengths to make the world a better place. It is also demanding of nonmoral factual information. But we can abstract from these difficulties in the present context. It is reasonable to conclude that it is all right to put an individual who will live a long and reasonably happy life into existence but that it is wrong to inflict pain on an infant whom you try in vain to rescue and that it is wrong, according to utilitarianism, to allow an infant to live if it will live a life that is not worth living.

Could the infant in the example be seen as, morally speaking, replaceable? Yes, indeed. Everyone is morally replaceable according to utilitarianism.

However, psychologically speaking, we are rarely replaceable. Our close ones get sad (hopefully) when we die. However, in principle and morally speaking, everyone is replaceable according to utilitarianism. And when we consider the infant in our example, who has just been born with a poor prognosis and to whom the parents have not had a chance to attach, it may indeed be an option for the parents to go for a replacement. These parents may well (and for good reasons according to utilitarianism) contemplate having another child who is healthy in its stead.

WHO SHOULD DECIDE?

We could modify the example in various ways. If we make the prognosis more optimistic, then there is probably a point in which all people, including the adherents of the 3 views under discussion, would

agree that we should attempt to save the life of the child. The important lesson we have learned so far is that adherents of different views are bound to end up with conflicting practical recommendations in some situations. Whereas the adherents of 1 view claim that the life of the child should be saved, the adherents of another view will claim that the child should be allowed to die. What are we to make of this philosophical disagreement? After all, all 3 of the conflicting basic moral principles have clever and contemporary advocates. It is a nonstarter to try to establish that a common view exists here among the experts.

It is of note that not long ago, according to Swedish legal practice, a fetus at 26 weeks' gestation could be aborted. Now, the time limit for abortion is 22 weeks. The change of legal practice has nothing to do with intrinsic properties of the fetus or child. The crucial thing is the advance of intensive neonatal care. According to Swedish legal tradition, it is not permissible to abort a fetus that is viable. And the viability depends entirely on the development of neonatal intensive care.

The legal situation is different in other countries. However, philosophically speaking, it is obvious that it is not a good idea to rely on viability. Viability has nothing to do with the development of the fetus and everything to do with medical scientific progress. Viability is not an intrinsic property of the infant. There may come a time when the entire pregnancy can be sustained by an artificial womb. This reveals that we need other criteria. Here is my suggestion as to how such a rule should be devised. I have made this recommendation for several years now since 2009.

Parents should be granted an absolute right to a veto against additional treatment of the child in situations in which philosophers disagree. When fundamental

disagreement between philosophers exist and reasonable arguments can be given in defense of theories in which conflicting practical recommendations are issued, the parents should decide. At least they should have a right to a veto against any attempt to save the life of the child.

The simple case is the negative one in which the parents do not want the child to be saved. But what are we to say about the cases in which they want the child to be saved, but utilitarians and moral rights theorists protest and claim that this is way too risky? Should the parents have the right to require that the life of the child be saved also in such situations? I think not. This assessment may be seen as biased in favor of utilitarianism and the moral rights theory and against the sanctity-of-life doctrine, but I think there is a way to show that this practice is consistent even with this theory.

In a medical context, one has to acknowledge that economic constraints exist. To make attempts to save the life of the neonate when the odds are extremely bad (in situations in which both utilitarians and moral rights theorists argue that it is wrong to attempt to save the life of the child), it is not cost effective to make an attempt. It is highly likely that the attempt may fail.

It is true that there are studies that indicate that it is indeed cost effective to save the life of an infant at 23 weeks' gestation.² But this result is only assumed to be true of the infants themselves, not of their mothers (no mention of their fathers). Moreover, many of the assumptions made in this calculus are bogus.

First of all, with the measurement that they used (qualitatively adjusted life years gained), the authors do not take into account the fact that some lives may not be worth living. This may be so with some of the infants who are saved to short lives in

terrible conditions that end in painful deaths. These are the numbers given in the study: “Neonatal QALYs were estimated by applying the neonatal utilities for adolescent survivors of extreme prematurity (1.0 for intact survivors, and 0.83, 0.69 or 0.23 for mild, moderate or severe sequelae, respectively).”²

Secondly, even if it is possible to adapt to disabilities of various sorts, the assessment of them seems to be overly optimistic also with mild disabilities. The problem is not the disability as such but the fact that if you have, say, a personality disorder, such as attention-deficit/hyperactivity disorder,³ or just low intelligence, or autism,⁴ the risk that you will end up in unemployment or even prison is increased.⁵ There are relational problems with many of the milder forms of diseases. And intelligence is indeed an issue.

Thirdly, when we make our assessments, we should look not only on the future of the child who is being saved but also on the costs to provide the child with good living conditions (publicly financed assistance and so forth if the child suffers from serious disabilities). In a well-functioning welfare state, these costs are huge, and the competition for them is fierce. And even if it makes good moral sense to provide a person with expensive needs expensive treatment and care, it is still a fact that had this patient not existed but another individual who is healthy in its stead, the resources we now spend on this patient could have been spent elsewhere. So, there are opportunity costs we could avoid if we adopt a more conservative assessment of when we should invest in the care of neonates with a poor or problematic prognosis.

Finally, we should bear in mind that rather than putting the resources into this infant with a bleak prognosis, the parents could make another attempt to have another child without complications. I believe many would

do so if this was provided as a reasonable way out when the parents are being counseled.

Even the adherents of the sanctity-of-life doctrine must accept that economic constraints exist within the health care system. If too heroic measures are taken to save the lives of extremely premature infants, then there are other categories of patients who have to carry the opportunity costs.

When we spend resources on these other patients rather than on the controversial and next to hopeless cases in the neonatal care setting, this means that we foresee that some neonates will die, but this is not something we intend. It is a mere foreseen effect of our effort to save as many lives as possible within the health care system.

The adherents of the sanctity-of-life doctrine should be prepared to accept this.

CONCLUSIONS

Suppose we try to establish a system along the lines that are adumbrated here. Then as a general rule, the parents are granted a veto against any attempts to save a child when there is reasonable disagreement among philosophers about whether the life of the child should be saved. This can happen with extremely premature infants, but it can also happen somewhat later on when the prognosis is poor. In particular, if parents are prepared instead to have another child who is healthy, this is to be recommended. It is the recommendation that both a utilitarian and a moral rights theorist would give.

I have received objection⁶ that there are many other cases in which it is difficult to tell whether an attempt to save a life should be made. My suggested rule does not address them.

This is true, of course. However, this is not a problem with the rule as such. The discussion of these other cases must await some other occasion. And in general, as noted above, there should at least exist a presumption against saving the life of a child with poor prognosis regardless of age if the parents are against the decision to do so.

This is the easy part of discussion. But what are we to say of the parents who demand additional attempts to save a child (when the profession disagrees) and disagree with support from both utilitarians and adherents of the moral rights theory but agree with adherents of the sanctity-of-life doctrine who believe that attempts to save the life of the child should be made?

My suggestion is that one should establish a rule of a conspicuous nature that refers to indisputable things such as time limits.

I think that as a rule, it would be a good idea not to attempt to save children who are born before 24 weeks' gestation. (Now and then it might be necessary to adjust this age limit, as science develops. It is based on the most recent research. New data may render a stricter rule or a more permissive one reasonable.) I submit that this is the rule we should use. It should be the point of departure when parents are counseled. We should look to it as a rule of thumb.

One may also add that even if consciousness as such is of no moral importance to any of the moral theories discussed in this article, it is reasonable to assume that consciousness sets on at 24 weeks.⁷ From the point of view of common sense, this might be an additional reason to adhere to the limit that is suggested here.

A double rationale exists behind it. First of all, half of the children who are born at 23 weeks' gestation do not survive, and a majority among

those who do survive do so with disabilities.⁸ Secondly, and for this reason (the poor outcome), it is not cost effective (when societal costs are considered) to undertake attempts to save these infants. In particular, this is true if we see a new attempt to have a healthy child as the alternative to any attempt to save the neonate.

Yet, there may exist cases in which it is necessary to depart from this rule. However, these cases should be rare. I think of cases in which the parents are adamant that they want all attempts to be made to save their child, that they have come to the conclusion that this is their last

chance to have a child, and that they are prepared to take on the special burdens associated with a child with severe disabilities. If the parents insist, it might be necessary to make an exception from the rule and honor their strong wish.

One can compare this example with that of Jehovah's Witnesses who need surgery but cannot accept blood transfusions. They are sometimes offered extremely expensive surgical measures to minimize the risk that they will need a blood transfusion.⁹ The same is true of parents who feel that for moral or psychological (or both) reasons, they cannot let

go of the early infant and seek a replacement for it in another child who is hopefully healthy.

The rule should be to err on the right side and make no attempt to save a child who is born before 24 weeks' gestation. Such a policy has a rationale in utilitarian and moral rights thinking, according to which the best move for the parents is to attempt to have another child who is healthy, and it can also be accepted from the point of view of the sanctity-of-life doctrine once the opportunity costs of deviating from it are taken into account.

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