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Parental Consent and the Use of Dead Children’s Bodies

ABSTRACT. It has recently become known that, in Liverpool and elsewhere, parts of children’s bodies were taken postmortem and used for research without the parents being told. But should parental consent be sought before using children’s corpses for medical purposes? This paper presents the view that parental consent is overrated. Arguments are rejected for consent from dead children’s interests, property rights, family autonomy, and religious freedom. The only direct reason to get parental consent is to avoid distressing the parents, which carries implications for the consent process, secret harvesting of body parts, and the weight to be given to parental feelings.

In 1999, it was made public that Europe’s busiest children’s hospital, the Alder Hey Royal Liverpool Children’s Hospital, had 2500 pots containing the organs of dead children. The organs had been taken post mortem, supposedly for research, but although the parents either had consented to the postmortems, or at least knew that they had been ordered by the coroner, they did not know that the organs of their children were being removed and stored. The organs were taken secretly. About the same time, it transpired that children’s organs were taken without consent in Bristol too. The resulting public outcry prompted several enquiries and a nationwide census of organs held. It was found, depressingly, that not only were the organs of children and adults taken without proper consent on a massive scale, but also in many cases they were merely stored and not used. So far, the scale of the misuse of children’s organs in the U.K. far surpasses that found in other countries, where there apparently have been localized instances.1

Whoever was responsible for the failures of oversight that allowed the misuse to go on, it seems clear that the decisions to take the organs were...
made within hospitals by doctors. It is not clear, in these scandals, whether
doctors broke the law in taking organs without parental knowledge, nor
whether parents would have any remedy. Still, the widespread outrage
generated by the actions of the doctors was not about whether they had
acted illegally. The outrage was felt because the doctors were thought to
have acted immorally. They bypassed parental consent and they did so
not through oversight but through a policy of secrecy, or so it appeared to
the mind of a public grown rather distrustful of the medical profession.
The public’s objection was not, then, to the practice of research on dead
children. Although some think that research on dead children should not
be allowed under any circumstances, that belief was not to the fore here.
The objection was to the secrecy and betrayal involved and, primarily, to
the failure to get parental consent.

It is useful to construct a slightly more precise account of what I think
are commonly held views on parental consent to the use of dead children’s
bodies. This account claims that parental consent is, except perhaps in
dire emergencies, necessary for the legitimate use of dead children’s bod-
ies. This claim gives a great deal of weight to parental consent. It rules out
both secret and overt conscription of the bodies of dead children for re-
search or transplants even if such conscription is needed to save people’s
lives. Furthermore, the account holds not only that parental consent is
necessary for the use of bodies to be legitimate, but also that it is a pow-
erful support for using them. Parental consent takes care of the family
members’ interests in the use of the bodies. Finally, if parental consent is
to legitimate the use of the bodies, it must satisfy the usual requirements
of informed consent, in particular those pertaining to the adequate under-
standing of properly disclosed facts. These claims make up the position
that parents have the right to give or to withhold informed consent, which,
for convenience, I shall call the “rights of consent.”

There is so much to object to in what happened in Liverpool and else-
where that the central matter of parental consent has been underexamined.
This paper questions the basis of parental rights of consent and asks
whether and why it would be morally wrong not to get such consent to
the use of the bodies of dead children. I argue that there is a reason to get
parental permission, namely to avoid further distressing them in their
grief. I also defend the more controversial view that it is the only direct
reason to seek consent. I think it follows that the common view is wrong
and that parents should not have the status of having rights of consent,
but only the (lesser) status of people whose feelings should be taken into
account. I shall argue that if avoiding distress is the reason to ask parents’ permission, then the claim about the weight of consent and even the claim about satisfying the requirements of informed consent will not be justified.

The first part of the paper is negative: it rejects a number of reasons for parental consent to the use of dead children. The reasons I reject include interests of the children, property rights, family autonomy, and religion and culture. The second part of the paper is more constructive, developing what I take to be the correct account of the importance of asking parents’ permission. I claim that the only direct reason to ask parental permission is to avoid causing them more distress, and I point out some of the controversial implications of this claim for the wrongness of secrecy, the consent process, and the weight that parental consent should have. I then defend the claim against the objection that it wrongly gives weight to anyone’s distress and not just the parents and I deal, finally, with some recalcitrant intuitions.

In this paper, I generally focus on parents, rather than families or next-of-kin. I do so because parental consent is the most common case and the one to which the arguments for proxy consent for children are best suited. If parental consent is difficult to justify, it is even more difficult to justify consent for other proxies. Toward the end of the paper, however, I briefly consider circumstances when the wider family and not just the parents should be asked.

Finally, children’s dead bodies could be used for research, transplantation, or teaching purposes. This paper does not discuss the moral differences between these uses. It deals with the ethics of the supply side of body use rather than the demand side, focusing on the degree to which parents’ views should be taken into account in formulating policy on the use of dead children’s bodies.

THE INTERESTS OF THE CHILD, AND DIGNITY

A major reason for seeking parents’ consent before treating or doing research on their live children is to protect their children’s interests. The thought is that parents know their children best and care the most about them, so they are the best protectors of their children’s interests. However, dead children, at least below some age, can have no interests that survive their deaths. So giving parents rights of consent cannot be justified on the grounds that it will best protect their children’s interests.

Some will find it obviously true that dead children cannot have interests that survive their deaths because they believe that no one can. The argument
for parental consent from dead children’s interests will be a non-starter for those who deny the possibility of posthumous harm. I do not want to argue that posthumous harm is impossible, however. Indeed, I think that people can have interests that survive their deaths (see, e.g., Feinberg 1984, pp. 79–95). But, as it happens, I think that the kinds of interest that can survive a person’s death are ones that presuppose a fairly high degree of intellectual ability and that the interests usually will have to be ones that the person cared about. I say “as it happens” because I am not claiming that it is in the nature of interests as interests that they have to be cared about or presuppose high reflective ability. Living small children have interests in their development or in being fed, even if they do not and cannot realize this. I am just making the claims about reflection and caring for interests that can plausibly be affected by posthumous events (and interests in development or being fed obviously do not fall in this class). Living very young children do not, for example, have interests in reputation or privacy for their own sakes—that is, leaving aside any instrumental effects such as how their reputations affect the behavior of others toward them—because they do not understand the concepts, which in turn must be understood in order to count as interests. If very young living children do not have these interests, it would be very surprising if very young dead children did.

Similar things can be said of an interest in what happens to one’s body after death. People who do not care probably do not and those who cannot care cannot have any such interest. Thus while adults and older children might have reasonably well-worked out views about what should happen to their bodies after death, and so might have an interest in their bodies not being used for medical purposes, younger children will not. Younger children will not have an interest in their bodies not being used after death because they have no conception of death that would be sufficiently well worked out to ground such an interest. There is universal agreement, at least in the universe of psychologists, that preschool children do not understand death in the same way that adults do. They do not understand that death is irreversible, for instance, or that it is inevitable (Slaughter, Jaakkola, and Carey 1999, p. 73). Admittedly, it will be a matter of controversy at what age children tend to conceive of death accurately, so I will stipulate that, in the rest of this paper, I shall be talking of children who uncontroversially do not. Preschool children, at least, do not have posthumous interests relevant to this paper.

The claim that very young children do not have posthumous interests is supposed to be uncontroversial. I do not think it presupposes anything,
for instance, about whether living infants are persons, or whether they have potential interests that can ground duties for others. More could be said in defense of the claim if necessary, but I think it is unlikely, given what has been said so far, that anyone would seriously push for parental rights to consent on the basis of their children’s posthumous interests. Admittedly, some will hold, in virtue of their religious beliefs about an afterlife, that even very young children can have posthumous interests, so my claim is not entirely uncontroversial. However, I postpone discussion of this source of controversy to a later section.

The only potentially plausible argument from children’s posthumous interests is that children can have interests in their bodies not being used because they, like everyone, have an interest in their remains being treated with dignity. Adults have different beliefs about what would count as a dignified use of their remains, and many think that their beliefs should be respected. It is fairly straightforward to argue from dignity to consent in the case of adults. The situation of dead children, however, differs in several respects from that of adults. The first significant disanalogy is that, unlike adults, very young children do not and cannot care about their remains. On the view, previously outlined—that it is a necessary condition of one’s having an interest in something that one could care about it—it follows that very young children do not have an interest in the dignified disposal of their remains.

Some would reject the connection between interests and the potential to care and would assert that very young children can and do have interests in dignity. However, we need not go into the general claim about interests because the argument from dignity can be reformulated. It might be said that we have duties to treat the remains of children with dignity, regardless of whether children have an interest in such treatment. It would surely be wrong, for instance, to display a child’s remains in a circus whatever the parents think, and that conclusion holds regardless of whether it is formulated in terms of the child’s interests.

Notice the way in which the conclusion is put. It would be wrong to display the remains in a circus whatever the parents think. There is a crucial difference here between adults and children; there is no straightforward case for parental consent from an appeal to the dignity of the child. The case for consent to the disposition of one’s remains in the case of adults hinges on the variety of ways in which one might choose to be treated with dignity and the importance of deciding this for oneself. But children’s interests in dignity do not vary in the way that adults’ interests
do, because children of the age with which we are concerned do not have the required difference in attitudes or lives. The inference from dignity to consent is thus blocked, and the question of dignity instead comes to this: is it consistent (or inconsistent) with dignity to use the remains of the children for medical purposes. Whatever the answer is, it could not vary from case to case in the way it actually does with adults, and so there is no need on that account to get parental consent. Indeed, if it is inconsistent with dignity to use children’s remains in certain ways, then that is a reason not to let even parents give consent for such uses, just as we would not permit them to display the remains in a circus.

Is it then inconsistent with the dignity of children to use their remains for medical purposes? This is a large, and difficult, question. One reason to think a circus display undignified is the trivial and unwholesome use to which the remains are put. Using the bodies of children to save lives or to reduce the effects of disease and disability is neither trivial nor unwholesome. Thus, insofar as dignity depends on use, that use would not be contrary to dignity. The argument probably is not sufficient to show that medical use is consistent with dignity, but not much more can be said until we have an account of dignity applied to this topic. One possibility is that the use for medical purposes conflicts with children’s dignity because it treats them solely as a means to an end. This seems to me to replace the obscurity of “dignity” with the obscurity of “treating solely as a means.” Be that as it may, it is not obvious that using the remains of children for medical purposes is to treat them solely as a means and to fail to treat them as an end. Treating them solely as a means would be to treat the bodies as if they were mere things to be used or discarded in whatever way one chooses with no more respect than one shows to scalpels or surgical gloves. This may be the way bodies are sometimes treated, but it need not be, and some effort often is put into using bodies in a dignified way. Some might say that that is not enough to show that the bodies are being treated as more than mere means; again, however, it would help if such respondents were to develop their objection more fully.

Even if using the bodies of the children would be inconsistent with dignity, it would not follow that doing so is wrong. Given the significant difference between children and adults in that children cannot care about dignity, dignity must have more weight in the case of the adults. But the case here does not rest on dignity’s being a weak reason. It rests on the denial that dignity either rules out the use of bodies or justifies parental consent.
Another potential argument to justify parents having rights of consent over their dead children’s bodies appeals to an alleged property right that parents have in their dead children’s bodies. If understood in a legal sense, the claim may or may not be true, depending on the jurisdiction. In English law and legal systems that follow it, however, the claim is not true. A common law rule dictates that there is no property in dead bodies.\footnote{7} Be that as it may, should parents have property rights? The costs of saying so are formidable: if dead children can be owned, why not live ones? If dead children can be owned, why couldn’t their corpses be sold, mutilated, or displayed in public for a fee? Why is it only parents or other relatives who can acquire property rights? Indeed, the problems of developing a property argument are so formidable that I do not think it is worth detailed discussion here.\footnote{8}

What, though, of the intuitions that lead some in the direction of a property argument? Consider the argument that because parents put their skill, effort, or genes into producing and rearing their children, they should get a special status. The thought is that, just as a painter should have a special say over her picture, parents as creators should have a special say over their children’s bodies. But to my mind this argument is offered by people groping for a conclusion, the conclusion that parents have special status. A sign of this is that no one thinks that a hardworking team in a neonatal intensive care unit should get even a proportionate say in what happens to the child’s body. It is not as if their rights are overridden by the parents’ rights. They have no such right at all. Effort and skill really have nothing to do with it; nor do genes alone. Sperm donors, simply through being genetically related, do not acquire such rights.

Still, if parents do not own the bodies of their children, who does? Hardly anyone will want to say that doctors or researchers own the bodies, or even that the state does. It might be thought that someone has to own the bodies and, if not the parents, it must be someone or something less palatable. But such a view is a mistake based on a conflation of control and ownership. Consider a policy of overt conscription of bodies where the state can decide whether to authorize doctors to use them, but where it is only permitted to do so for medically sound purposes. This policy gives the state a limited amount of control, but it no more gives the state or doctors a property right in bodies than its right and duty to raise taxes for public benefit gives the state or its agents a property right in the revenues. Of course, this is a skeletal description of a policy, and some
may doubt that it could be designed to avoid abuse successfully. Others will believe the policy fundamentally wrong. The point here is not to be misled into thinking the policy wrong because it undesirably gives property rights to the state or doctors. It gives property rights to no one.

The rest of this section considers more promising arguments in the literature for family autonomy and parental rights over their living children. However, as with property, it denies that these are good arguments for parental consent in the case of dead children. Consider what is probably a common view of family autonomy and parental decision-making authority. Families have collective interests that are not reducible to the interests of individual members (and in fact may conflict with them). Parents should decide, within limits, what these collective interests are and what weight they should have. Applied to the use of dead bodies, it might be said that the disposal of family members’ remains is a collective interest of the family and the parents should decide how it should be done.9

There are many hard questions to be asked of this view. The most obvious is how far parents should be able to act against their children’s interests without interference. My interest, however, is in the justifications that might be offered for parental authority and whether they show that the disposal of bodies should be the subject of parental rights of consent. I shall consider here the two most plausible arguments I know for parental authority that might help to make the case for parents as consenters. The first argument is made by Ferdinand Schoeman (1980, 1985) for family autonomy from the value of intimacy. This can be thought of as a description of a collective good, intimacy, that benefits all family members and requires parental authority. The second is Edgar Page’s (1984) argument from the value of parenthood, which derives parental rights from the interests of parents and the collective interests of society, rather than of the family.10

Schoeman argues that, apart from situations of great risk to the child, the state should protect the parent-child relationship by leaving parents a wide sphere of responsibility and, within that sphere, abstaining from scrutinizing it or interfering with it. The basis for his argument is a mix of conceptual and psychological points about the conditions for intimacy and a claim about its value. Intimacy, he thinks, involves a sharing of the self, marked by an inner commitment between intimate parties, and intimate relationships require that parties set their own terms. If the state tried to regulate relationships, it would tend to drive out inner commitment, undermine trust, and deny parties the space they need to construct
their own relationships. Consequently intimacy would be undermined. On the assumption that someone needs to speak for dependent young children, it ought to be the parents because the alternative is intimacy-undermining regulation. A source of intimacy in the relationship between parents and children would be lost, and that would be bad not just for the parents but also for the children (Schoeman 1984, pp. 14–19).

Whatever the merits of Schoeman’s argument, there is a fundamental problem with trying to apply it in the context of the dead. There cannot be intimacy between the living and the dead (the dead have no selves to share). One might claim that the relationship between parents and their living children would suffer if it were known that dead children were liable to be conscripted. But is that a plausible concern? As stated, Schoeman’s arguments are a mix of conceptual and psychological points. Conceptually speaking, it is hard to see why intimacy between the living would require control over the dead. Psychologically it might, although it seems very unlikely. And, while we are considering the psychological component, note that a policy of secret conscription could not, if kept secret, affect that component because it could not affect parents’ feelings for their children. There are other objections to secrecy besides intimacy, and some of these are presented in a later section, but for now the conclusion is that a concern for intimacy almost certainly would not justify giving parents the status of consenters.

Consider now Page’s (1984, pp. 195–202) argument for parental rights from the value of parenthood. Page argues that parents want to shape their children’s lives, to fix their basic values and broad attitudes, and to lay the foundations of their lifestyles. He thinks that parental rights to consent to medical treatment, to determine a child’s religion, and so forth, serve parents’ interest in shaping their children. But he argues that that interest alone is not enough to justify parental rights; it is a necessary part of their justification that such rights define a valuable practice of parenthood. Leaving aside the question of whether Page’s account of the practice of parenthood is widely applicable, does the value of parenthood justify parental rights of consent over their dead children’s bodies?

One could deny that the value of parenthood is weighty enough to establish such rights of consent. One might claim that control over dead bodies is not an aspect of parenthood that is sufficient to outweigh the reasons to use the bodies. I am inclined to go further. I do not think that the value of parenthood, on Page’s account, provides even a defeasible reason for parental rights of consent in this case. Page bases parental
rights on an interest in shaping children’s lives. But that interest is not affected by the use of dead children’s bodies because such use is not an aspect of those children’s lives, even metaphorically speaking. For adults, it might be that, in a metaphorical sense, one should think of the use of their corpses as an aspect of their lives. But this is simply a variant of the idea of posthumous interests. Just as children cannot have posthumous interests, neither should the use of their corpses be viewed as an aspect of their lives, and still less should controlling such use be understood as an element of the value of parenthood. Of course this is not to say that parents will not have views about what happens to their dead children’s bodies. The point is that those views cannot plausibly be brought under the label of shaping their children’s lives and, consequently, should not be protected as a part of that interest.

I began the discussion of family autonomy with a picture of the family as an entity with collective interests not reducible to the interests of individual members. Those who find such a picture attractive may well feel that, in limiting the discussion to intimacy and shaping lives, something important has been left out. Surely, they might say, there is some value in the family relationship apart from those, and it is something that society and the state should honor and protect. That may be so. But, apart from the ones already considered, I am not aware of any arguments for or explanations of this value that have the detail necessary to ground the conclusion that parents have the rights of consent described at the outset of this paper. To put it uncharitably, all that the defenders of family autonomy have offered in answering the question about dead children are promissory notes.

RELIGION, CULTURE, AND CONSENT

Some parents have religious or cultural beliefs that lead them to oppose the use of their children’s organs. Do these beliefs support parental consent? I shall argue that they do not, except insofar as parents with those beliefs would be distressed if their children were used. But before the argument, an admission: this is a difficult topic and because it is impossible to do it justice in a short space, what I now say is underdeveloped. For instance, there surely are important differences between the reasons that Jehovah’s Witnesses, Orthodox Jews, Chinese, or Maori have for desiring intact burial, but I do not go into these.

Consider two ways in which religious or cultural beliefs might be applied in defense of parental rights of consent. First, one might say that the beliefs support the rights because they are true; and second, one might
say instead, or in addition, that, regardless of whether the beliefs are true, considerations of religious or cultural freedom entitle the parents to act on them.

Take an argument that relies on the religious or cultural beliefs being true. The argument might be that children's bodies should not be used because God has forbidden it or because the children would face a worse, or no, afterlife. Note here that the connection with parental rights of consent is limited; parents would have the right (and duty) to withhold consent and no right to give consent. Other arguments might be along the lines that God wants parents to make the decisions for themselves and so parents would have rights of consent on this religious basis, if not others.

One can reply to these arguments by claiming that they are false in their factual premises and/or in their inferences to parents' rights. Believers of various kinds have to accept that some such arguments must be false in facts or inferences since they are mutually contradictory. Atheists will think that all the arguments are unsound. A different reply is to say that the state should not take into account the truth or falsity of beliefs about religion. In a neutral or free state, arguments that rely on the truth of the beliefs are not suitable for public reasoning. And, as we saw, some religious beliefs would not establish rights of consent since the beliefs condemn giving consent. To my mind, there is great weight both in the first reply, which denies that the religious or cultural arguments are sound and in the second, which holds that their soundness is irrelevant.

This leads to the issue of religious or cultural freedom. Even someone who disagrees with people's beliefs can think they should be free to act on them, and thus it might be said that it is a denial of religious or cultural freedom for parents not to have rights of consent (see e.g., Muyskens 1981, p. 194; Feinberg 1992, p. 113). One can ask, however, whose religious freedom is at stake. The desired conclusion of the argument is that the parents and only the parents should have the power to give or withhold consent. But that does not follow from holding that religious freedom is important. Suppose a religious outsider would be outraged if any parents consented to the use of their dead child. Is that outsider's religious freedom at stake if parents are allowed to consent? Should she have veto power over what parents do? To say that religious freedom is important does not answer those questions one way or the other.

Indeed it is not clear what the connection is between religious freedom and control over the disposal of bodies. We have a clear sense of religious freedom as freedom from certain kinds of interference; freedom from per-
secution, for instance. But that freedom does not give us control rights over bodies. It is plausible to argue that one should be able to control what happens to one’s own body and one could use that control to implement one’s religious beliefs. But note there that religious freedom is not doing much work in justifying control. Control depends on other justifications.

Suppose we want to say, as we surely do, that the religious outsider who is excluded from having a say is not thereby having her religious freedom infringed upon. The problem is in saying whose religious freedom would be infringed upon if the dead child’s body were conscripted. The dead child’s religious freedom cannot be. Regardless of whether dead people can ever have religious interests that survive their deaths, the children we are talking of will not, because they never had religious beliefs in the first place. So presumably, then, it is the parents’ religious freedom that is supposed to matter. But why should that be? It is not their bodies that are at stake. It is the bodies of their children.

In sum, the argument from religious or cultural freedom is incomplete as an attempt to justify parental permission. Without some further premises, there is no reason to take into account only the parents’ religious beliefs as opposed to anyone’s or no one’s, and there is no explanation of the link between religious freedom and control over the disposal of bodies. So far, we do not have those premises. My view, which I cannot fully defend here, is that the force of religious or cultural beliefs in grounding parental consent reduces to the force of not distressing the parents. There is still a problem of explaining why it is only the parents whose distress would count, but I think I address that concern adequately at the end of the paper.

Having rejected a number of arguments for parental consent in the use of dead children’s bodies, I now try to construct a better account of the reasons for taking note of parents’ wishes. I begin by explaining what I take the role of distress to be in supporting parental consent.

PARENTAL CONSENT AND THE AVOIDANCE OF DISTRESS

Parents might have all sorts of reasons for wanting to be asked before their children’s bodies are used. For most of them, the death of their child will be an awful time, and they will feel powerless enough without losing control over the body of their child. Here, the wish is to be asked rather than to withhold consent. Some will, however, want to be asked so that they can refuse. They might want to refuse for the religious or cultural reasons just discussed, but they might want to refuse for other reasons.
too—after all, even non-religious families can think it important that their loved ones should be given a decent burial.

The parents’ feelings create a reason to ask their permission. The reason is to avoid further distressing the parents. This reason is only a contingent one however. Although many parents would be upset if they were not asked, some would not be. Some parents might, for instance, be satisfied with being notified or consulted about the use of their children’s bodies as opposed to having veto power over it. However, although the connection between reducing distress and getting permission is only contingent, it is probably the most important one for developing policies for getting consent, and it is the one I shall focus on here.

The underlying intuition is that there is generally a reason not to cause people distress. That reason is, of course, a defeasible one because sometimes, all things considered, causing distress would be justified. But in the present cases, it provides at least one reason not to use the bodies of dead children without parental permission and, if there were no good reason against it, then it would be decisive.14

Now some will not see avoiding distress as the primary reason to seek consent. They will think that parents should be asked because the matter involves their children. According to this view, parents will think they should have the status of consenters and, although they will be upset if they are not asked, their distress stems from these beliefs about status, which, if sound, would directly provide a reason for consent. The view I shall defend, by contrast, is that such beliefs are not sound and that it is the distress and not the beliefs that provide a reason to get parental permission.

I shall call the view I am defending the “distress view.” The distress view has the following features:

(1) Avoiding distress is often a defeasible reason for getting parental permission.
(2) Avoiding distress is the only direct reason for getting parental permission.

This second claim needs explaining. There may indeed be reasons besides distress for getting parental permission, such as the need to avoid damaging public trust in doctors. But these kinds of reasons are side effects, rather than being directly rooted in parents’ reactions. Avoiding distress, on the other hand, provides a reason that is directly rooted and, according to the distress view, provides the only one.
I have not produced decisive arguments for or a full account of the distress view. For instance, one may doubt that distress is always even a defeasible reason to ask parents. Perhaps, one may think, we should give no weight to the distress caused to some parents by using their children’s organs because only parents who are thoughtless or uncaring would experience that distress.\(^\text{15}\) And, of course, one may doubt the claim that distress is the only reason for getting parental permission since, even if what I have said so far is right, I have only disposed of some further alleged reasons, and not shown that there are none.

Despite not having a full account of the distress view, we have enough to see some of its implications, and I now examine those for informed consent, secrecy, and the weight that should be given to parental consent. But before going further, one last point should be stressed: in referring to the distress of the parents I do not mean to trivialize their feelings. Those who take “distress” to be too weak a term should substitute some other.

**Distress and Informed Consent**

Suppose that the only reason to seek parental consent is to avoid further distressing the parents. That implies that the process of getting permission should be designed with a view to distressing parents as little as possible. It does not imply that the process should be designed to elicit informed consent, unless that happens to be the way to minimize parental distress.

To see the difference, let me briefly explain the relevant requirements of informed consent (see Beauchamp and Childress 1994, pp. 128ff.). If someone’s consent is to be informed, then the salient facts must be disclosed and the person must, at the time of deciding, understand and perhaps care about those facts and her decision. The aim of informed consent normally is to protect the autonomy and well-being of the subjects or patients and not to minimize distress. Indeed minimizing distress may conflict with informed consent. It is usually a (possibly justifiable) derogation from informed consent not to tell patients about their condition if doing so would upset them.

I claim that in the case of dead children the point of getting parents’ permission is to avoid distressing them rather than to get genuinely informed consent. This is significant. It is sometimes objected that parents cannot give genuinely informed consent shortly after learning of a child’s death because they are too distraught to be able to take in the information. The conclusion is often drawn that the bodies should not be used if
consent is sought and given only at that time. On my view, this conclusion would not follow, and it would not matter whether parents could take in the information, unless they later thought they had been badly treated and were upset by that. Furthermore, because it would not matter, empirical information about people’s capacity to process information after experiencing the death of a loved one would not be directly relevant to assessing the legitimacy of parental consent. The sort of information needed would be about how to ask them in a way that minimizes their distress.

Consider now glossing over or failing to disclose details of the proposed research that would be likely to put parents off. Such actions or omissions would be a derogation from informed consent, but again on my view not ethically worrisome, unless parents subsequently felt that they had been duped.

Because the distress view justifies something less than informed consent, it is useful to use a different term; I shall speak of “permission” rather than “consent.”

**Distress and Secrecy**

One reason for outrage at the behavior of the doctors in Liverpool was that they had acted secretly on their own authorization. What is wrong with such secret behavior? There is an obvious direct objection if one thinks that parents should have rights of consent. Failing to disclose the use of children’s organs to their parents is failing to seek their informed consent. But would secrecy be wrong if the point of asking were to avoid distressing the parents? Indeed, if the point is to spare their feelings, why tell them anything about taking their children’s organs? What they do not know would not harm them in any morally relevant way. Can the distress view justify even the limited requirement to get parental permission? If it cannot and if avoiding distress is the only consideration, what could be said against secrecy?

It is true that there is no direct reason to reject secrecy if the reason to ask permission is to minimize distress. There are, however, other objections. The first is a prudential one. Secret policies often backfire simply because it is so hard to keep them secret. When the truth comes out, it is likely that public trust in doctors would be eroded further. Saliently here, it is also likely that parents would be even more upset than they would have been if asked in first place. So if one thinks there is a reason to avoid distressing parents, secrecy is probably a bad idea.
There are other objections to using children’s corpses without telling their parents. Consider two ways in which such behavior may occur. In the first, which seems to have happened in Liverpool and elsewhere, doctors and hospitals just decide to take the organs. One can quite reasonably ask: what gives them the right to do this? If private citizens are to decide, it should be the parents and not doctors. The doctors’ and hospitals’ attitude also smacks of an undesirable arrogance in symbolically placing themselves in an undeserved position of superiority over the parents. In the second, doctors might take organs with secret state authorization. Such a practice would be objectionable for a different reason: the state should be accountable to its citizens, and so it should not be pursuing secret policies unless there is some overwhelming reason for doing so.

Although the distress view would not directly prohibit secrecy, it would do so indirectly when combined with the point about the impracticality of secrecy. In addition, there are many other objections to secrecy that are independent of the view that parents should be consenters.

**Distress and the Weight of Parental Consent**

What does the distress view imply for overt conscription? Would overt conscription be wrong? The answer depends on the benefits of conscription versus the weight that should be attached to the parents’ distress.

There is not the space here to defend a full view about the weight that avoiding distress should have, so I shall adopt the limited aim of contrasting parental rights of consent with the permission justified by the distress view. If parents have rights of consent, then their consent is almost always necessary for the use of bodies to be legitimate. Bearing in mind that we have not yet found adequate reasons to justify this position, how does it, nonetheless, compare to the weight to be attached to parental permission required by the distress view?

Suppose that no unavoidable shortage of bodies is caused by parents having the power to veto their use but that the process of asking parental permission has some minor costs in convenience and time. If convenience and time are all that is at stake, parental consent should be sought both on the view that they have the rights of consent and on the distress view, and there is no need to decide the relative weights to be attached to consent by the different views of the status of parents.

Suppose now that seeking parental consent would cause a shortage of bodies and consequently that some people would die or suffer disability. Should parents be allowed to withhold their children’s bodies? In answer-
ing this question, the rights of consent view and the distress view will probably diverge. On the view that parents have rights of consent, getting consent would carry great, although perhaps not absolute, weight, and so parents probably ought to be able to withhold the bodies. But on the distress view, mere feelings of distress surely would carry less weight than saving lives or preventing disability. Put another way: Whatever the reason for holding that parents have rights of consent, that view would require a more serious shortage, with more people suffering worse, to justify overriding the wishes of the parents than would be required if the point of getting permission is merely to avoid parental distress.

PROBLEMS FOR THE DISTRESS VIEW

The distress view consists of two claims: (1) avoiding distress is a reason for getting parental permission, and (2) avoiding distress is the only direct reason for doing so. The distress view implies some fairly radical conclusions about the unimportance of genuinely informed consent, the wrongness of secrecy, and the weight that consent has. The distress view also faces two problems that I will discuss in this section. First, in giving weight to feelings of distress, the view gives a say not just to the parents but to anyone who feels distress. Second, there are certain recalcitrant intuitions left unexplained by the distress view.

My claim is that there is a defeasible reason not to distress people and that that is the basis for seeking parental permission to use the bodies of dead children. But, it might be said, not distressing people could extend to more than just the parents. Other family members could be greatly distressed too. Do they have a veto? What if an individual or a group unconnected to the family was greatly distressed, perhaps for some religious or moral reason, at the thought of research being done on dead children. Should that person or group also have veto power, and thus be able to override the permission of parents? Surely not. And yet how can one justify taking into account only the feelings of parents if the rationale to which one is appealing is to avoid distress? It might be said that because it seems that only the parents should have a say in the disposition of their children’s bodies, avoiding distress cannot be the sole reason for seeking their permission, and consequently we should return to the idea of parents having rights of consent.

I do not think we are led back to parents as consenters, however. Let us consider the outsider with the religious or moral objection and the problem case in which parents do want their child’s body used but the outsider
does not. In that case, the outsider’s distress is pitted against that of the parents. If the parents’ feelings are stronger, then minimizing distress will tell against allowing the outsider to veto their decision. Suppose one makes the generalization that the parents’ feelings will be by far the strongest. Then the policy should be to ask only the parents. Admittedly it is possible that there will be a (very) few exceptions where parental feelings are not so strong as those of outsiders. But policy cannot be based on such an off-chance, partly because doctors are not in a position to gauge the strength of distress of all the possible candidates for a veto. So these exceptions can be ignored.

I have been concerned here with cases where outsiders and parents disagree and argued that the outsider’s distress should be set aside. The argument raises problems worth mentioning, although there is not the space for a proper discussion. Could the lesser distress that individual outsiders feel outweigh the parents’ distress if there were enough outsiders? I am undecided about this, although intuitively it seems implausible. And what if the parents and the outsider agree in opposing the use of bodies from which others could benefit? Would their distress at the use combine to give greater weight to the opposition? I think so, but I also tentatively think that no matter how many would be upset, it would be permissible to use the bodies if needed to save life.

Another problem for the attempt to exclude outsiders might arise from the generalization about the strength of parents’ feelings. It may be said that that generalization is not true of all cultures. In some, children may be brought up in extended families and other members may feel as strongly about the dead child as the parents. If that is generally the case, avoiding distress would not justify giving parents the sole say. I am inclined to say that, in such cultures, parents probably should not have the sole say and some other policy of family consent would be needed. So I do not see the cultural point as an objection to the distress view but rather as indicating an alternative way of applying it.

Now for the question raised by the recalcitrant intuition. The distress view, as indicated in the problem of the outsider, is concerned only with the quantity of distress felt. Parents’ distress was decisive only because it was greater, not because it was their distress. But can it be right that the fact of their parenthood does not make a difference?

Suppose some parents strongly believe it would be wrong for their child’s body to be used for medical purposes. But suppose that, for whatever reasons, even if they knew their wishes were ignored, they would not be
distressed. The connection between ignoring their beliefs and distressing them is only contingent and suppose it does not obtain. Then the distress view would deny that there is any direct reason to respect the parents’ beliefs. The parents’ beliefs would have no more force than anyone else’s, that is, no force at all.

I confess to being troubled by the conclusion that there is no reason to respect the wishes of parents who are stoical enough not to be distressed if their wishes are ignored. It may be that the distress view is overlooking some fundamental reason for parental consent. On the other hand, it may be that the distress view could avoid the undesirable conclusion if it is supplemented by considerations of fairness and good policy. If avoiding distress is a good reason to respect the wishes of most parents, it might be unfair to stoical parents to ignore their wishes simply because of the unusual nature of their feelings and it would probably be bad policy to try to decide who, among the sets of parents, would be the least distressed at having their wishes ignored. Considerations of fairness and policy do something to explain away the recalcitrant intuition, but is it enough? I am not certain; those who would oppose the distress view might try to do better than I can to explain the intuition and offer it theoretical support.

CONCLUSION

To conclude: Parental consent is overrated. It is commonly thought that parents have rights of consent, that is that their properly informed consent has great weight in determining the legitimacy of using their children’s organs. I have denied that conclusion. The main arguments for parental proxy consent either do not apply in the case of dead children, as was largely true when considering the interests of the child and arguments based on family intimacy and the value of parenthood, or they do not really work, because they are objectionable, as property arguments often are, or seriously incomplete, as arguments from religious or cultural freedom are. Unless better arguments are forthcoming, it is unjustifiable to hold that parents should be consenters. Nonetheless, there is one (and only one) direct reason to get parental consent, which is to avoid distressing them. That claim, which I call the distress view, has fairly radical implications for the consent process, the wrongs of secrecy, and the weight that parental permission should have.

Finally, let me stress that one cannot determine public policy from what I have said here. One reason is because the weight to be attached to parental distress has not been fully specified, although I think it can be said
that distress alone is less important than saving lives. The paper is more fundamentally incomplete in not answering certain questions about how to assess the results of different sets of rules for parental consent. To assess rules, say one where parents actively have to give consent to the use of their child’s body, or one where they would actively have to withhold it, we would need to have some evidence about the effects such rules would have on the availability of different kinds of organs or bodies for various purposes. We would also need evidence about the importance of those purposes—e.g., the probability that the use of the bodies would save lives or improve quality of life. These are all difficult and controversial questions (for instance, some believe that transplantation is greatly overrated as a way of saving or improving lives). This paper does not deal with any of them. The argument in this paper does tell us the ways in which parental feelings should and should not be taken into account.

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NOTES

1. See, among many others, the following articles on the British Medical Journal website, www.bmj.com: Mark Hunter, “Alder Hey Report Condemns Doctors, Management, and Coroner,” (3 February 2001); Roger Dobson, “Bristol Parents Protest over Removal of Hearts,” (20 February 1999); Deirdre Tilmann Mahkorn, “German Prosecutor Investigates the Removal of Dead Babies’ Organs,” (8 January 2000). In response to these scandals, the Royal College of Pathologists issued Guidelines for the Retention of Tissues and Organs at Post-Mortem Examination, March 2000, which clearly set out requirements for obtaining relatives’ consent to the use of corpses and include a summary for relatives of their legal rights and the uses to which they may be asked to consent.

2. One might think, as James L. Muyskens (1981, pp. 196–97) does, that the more immediate benefits of certain kinds of transplants and the more remote benefits of research support different policies for acquiring organs. Barry S. Coller (1989, p. 491) similarly argues that use for transplants should take priority over use for research.

3. Some authors, like William G. Bartholome (1981, p. 272), doubt these claims about parents, but that scepticism is not relevant here.
4. One might argue, implausibly, that denying parents control over the disposal of their children’s bodies would be bad for living children because parents would be too reluctant to take them to hospitals. This kind of perverse incentives argument was offered in the nineteenth century against compulsory postmortems for those dying in poor hospitals (see Feinberg 1992, p. 112).

5. This point was suggested by an anonymous referee.

6. One might think that one avoids using someone “solely as a means” only if one gets the consent of that individual, but there are problems for that view in addition to those that I have mentioned in the context of very young children. Kant, at least, did not take the principle that way (for discussion, see Cohen 1995, pp. 238–42).

7. See Andrew Grubb (1998) for an account of the strange origins of this rule, which appears to date back to 1644. Grubb also describes apparent exceptions. The relevant one here is a right to possession of the body for the purpose of disposal, but this right would not help the case for parents having rights of consent. The right is a consequence of a duty to dispose of the body and does not ground an immunity against reallocating the duty to others besides the parents.

8. I am happy to send on request a more detailed discussion and rejection of property arguments.

9. I am grateful to Julie Pedroni for suggesting this argument.

10. Neither Schoeman nor Page considers the specific case of parental rights over the bodies of their dead children.

11. I regret that my summary of Page’s argument does not do justice to its subtlety.

12. Page’s argument can be thought of as a striking application of Joseph Raz’s (1994) theory of the justification of civil and political rights in liberal cultures.

13. Some believe that the religious or cultural freedom of communities matters too. Note that the problem I raise for grounding parental consent applies at least as strongly to community consent.

14. Taking parents’ distress into account might be a reason for other actions too. For instance, avoiding distress might be a reason not even to ask parents. Or it might be a reason to try to reduce distress by engaging in some campaign to persuade people to see the use of corpses for good purposes as routine.

15. Both John Harris and Eric Rakowski are rather scathing about relatives’ opposition to the use of cadavers (see the quotation from Harris and the surrounding text in Rakowski 1991, pp. 167–73).

16. One thing I have not considered here are cases in which the next-of-kin was not close to the dead child and would not experience distress if not asked
permission to use the body. Would there be a reason to ask the next-of-kin in those cases? And what about those children with no next-of-kin? Note that the distress view could not be said to be unfair to young orphans if it said that it would be better to use their bodies than those of children who had living parents. Unfairness presupposes that young orphans have surviving interests, which they do not.

REFERENCES


