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Volunteering Children for Medical Experiments

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A subject which has aroused considerable interest on the part of moralists is the legitimacy of proxy-consent by parents or guardians in non-therapeutic experimentation on children. By “non-therapeutic” is meant experimentation aimed at benefitting not the child itself, but other children. Two major positions have crystallized. These positions are 1) an absolutist one forbidding proxy-consent for non-therapeutic experiments on children in all cases (Ramsey, May), and 2) a moderate position allowing such consent on two conditions: if there is no discernible risk to the health of the child, and if there present at the same time the hope of significant benefit to others (McCormick, Curran, O'Donnell). I am in sympathy with the conclusion of the second group but do not agree with the arguments they adduce to support it. The argument offered by its principal exponent, Richard McCormick, seems especially questionable and will be treated extensively below.

1. Abortion and the Ethics of Medical Experimentation

The Supreme Court’s 1973 decision liberalizing abortion has complicated questions of medical experimentation. Some doctors have interpreted it as implicitly sanctioning a wide range of research on abortuses or on fetuses destined for abortion. The argument runs: “If you are allowed in a certain instance to kill a fetus (by aborting it), then a fortiori are you allowed to perform upon it less damaging experiments in view of potential benefit to others?” Among the experiments which these doctors would avoid in the abortion situation are those which would tend to keep the fetus alive, since that would be contrary to the wishes of the parent(s). They only type of experiment allowed would be one which would benefit not the subject of the experiment but only others.
According to Paul Ramsey this skews longstanding principles of medical ethics regulating experimentation. These principles have always required the experimenter to procure explicit and informed consent from a patient prior to engaging in a well-designed medical experiment upon that patient. Only when the state of the patient renders this impossible might one proceed to act upon a validly presumed consent. However, such presumed consent was restricted to those cases in which the experiment was the last therapeutic hope for the patient himself. The classical instance is called the “Good Samaritan” case. Here, since coma or other factors preclude explicit consent, a doctor may legitimately presume that the subject would consent to treatment indicated for his own benefit and would thus agree to experimental medicine if all other means were deemed futile.

Allowing non-therapeutic fetal experiments on those about to be aborted, while forbidding therapeutic experiments on them, transposes the traditional principles of experimentation. It legitimizes experimentation on an individual for the benefit of others and forbids it in the only cases where traditionally it was most clearly allowed, i.e., when the experiment is aimed at the benefit of the subject himself/herself. We must take care that this skewed logic as regards fetuses marked for abortion does not also generate a lax attitude in experiments on children who, like fetuses, have not fully developed their essential human potential.

2. Experimentation on Children: Different Opinions

In this paper, we will set aside the abortion question and concentrate on the moral principles which should govern experimental research on very young children who are considered by the vast majority to be persons morally and legally.

Since such children are incapable of formal consent, questions arise concerning whether and when parents may give proxy-consent for medical experiments to be performed upon them. Paul Ramsey hews to a strict line: proxy-consent is legitimate only when the experiment is the last hope for the child’s own recovery. It is permissible, in other words, only when the child itself is ill and the experiment clearly provides the last possible hope of cure for the child-subject of the experiment. Ramsey qualifies this rule by allowing experiments upon a child, even though it is not itself ill, if it lives in an area in which an infectious children’s disease actually rages as an epidemic. He cites the first inoculations of children with the Salk vaccine as a legitimate “exception” to the general rule. Even though there was a small risk that the vaccine itself might cause polio, in those years all children were at risk each summer from the raging poliomyelitis epidemic. Ramsey deems that the presence of this danger was sufficient to allow one to construe such experimental inoculations as “therapeutic” in a wide sense.

The Guidelines for Clinical Investigation adopted by the American Medical Association in 1966, took a broader view of the legitimacy of
parental proxy-consent and allowed it in some cases of non-therapeutic experiment. They set forth two conditions, both of which must be fulfilled together before a construction of presumed consent in the child could be permitted. Such experimentation is sanctioned 1) “only if the nature of the investigation is such that mentally competent adults would not be suitable subjects” and 2) only “under circumstances in which an informed and prudent adult would reasonably be expected to volunteer himself or his child as a subject”. The first condition envisions experiments necessary for research on the mentally retarded or in the case of diseases which do not primarily affect adults, but children. The second condition restricts non-therapeutic experiments to those cases wherein the risks foreseen are minimal or negligible. The first condition is rather objective and follows the indications of medical science. The second begets the further question of how to determine what would reasonably move an adult to volunteer himself or his/her child.

Ramsey claims that the AMA criteria beg a more basic question: whether one can ever proceed to presume consent in the case of young children. He argues that to presume the consent of a child is to treat the child not as a child but as an adult. The presumption is necessarily “false” since the child in fact does not have, nor ever had, an actual or habitual capacity to give or hold back consent. William May agrees with Ramsey and adds that the legitimacy of therapeutic experimentation on children is grounded not on a presumption of the child’s consent, but on the parents’ duty in charity to care for their children.

Ramsey continues that even if we grant, for the sake of argument, that proxy-consent be allowed in the case of children, it must be interpreted with utter strictness. This derives from the analogy with adults. Few adults would agree to the proposition that if they were unconscious they could become the subject of experiments for the benefit of others, even when such experiments entailed no discernible risk, but involved only “offensive touchings”. (Examples of these are taking a blood sample or performing a small transfusion.) Why then, argues Ramsey, would one deem it legitimate to volunteer our children in similar instances? The issue of non-therapeutic experimentation on children is prismatic, Ramsey continues, for it tests the seriousness with which we view the consent requirement in general.

I respect the care and reverence of the Ramsey-May approach, but I believe that paradoxically it may be at once overly cautious and potentially dangerous. In the first place Ramsey’s position denying the possibility of any presumption of consent on the part of a child establishes too strong a distinction between children and adults, a difference which will come back to haunt the conservative moralist in the abortion issue and in questions regarding defective newborns. It is morally safer and closer to the truth to construe both children and fetuses as full-fledged humans on the grounds that they share the same essential potentialities. As such they can be presumed also to share the same basic desires as adult humans. The fact
that they are not as yet subjects of actual or habitual choice does not seem relevant. If, because of these essential potencies, they share the same rights as adults in the medical situation, then why not the same responsibilities in relevantly similar cases?

Moreover, May’s attempt to derive our moral obligation to give consent for therapeutic experiments for the benefit of the child from the duty of charity incumbent upon parents seems, in itself, to demand a construction of the child’s desires by way of analogy with the desires of adults. We usually decide the demands of charity by asking ourselves what we would desire others to do for us in the same situation. It is done by consulting our own ordinary desires. In deciding whether it is an act of love to let a badly malformed infant die in certain circumstances, we imagine ourselves in the child’s place and ask what we ourselves would want others to do for us. And this is to construct consent in the child.

Other Catholic moralists agree with Ramsey in insisting on explicit informed consent from a competent adult patient in the case of non-therapeutic experimental research. But in such cases some would allow the next of kin to give proxy-consent on behalf of an incompetent adult or child if such experiment involved only minimal risk or minor discomfort to the patient (McCormick, Curran, O’Donnell). McCormick is the principal exponent of this view and I will analyze his arguments as representative.7

3. Analysis and Critique of McCormick’s Position

He begins by noting that as years passed, the strictness of the Nuremburg Code has gradually been moderated. This code demanded that the explicit consent of the subject was absolutely necessary and went on to underline that this meant that “the person involved should have a legal capacity to give consent”.8 As evidence of a relaxation he cites the 1966 AMA guidelines and the 1973 HEW document entitled Protection of Human Subjects: Policies and Procedures.9 The latter forbids non-therapeutic experiments which are risky, but approves of non-therapeutic experiments on the basis of proxy-consent when there is “little risk and where the potential benefit is clear”. It further specifies that the information to be gained must be unobtainable in other ways and that the potential benefit to mankind must be significant and far outweigh the risk.

McCormick agrees with the practical conclusions of these studies and himself allows proxy-consent where there is no discernible risk or undue discomfort in a non-therapeutic experiment.10 He defends these conclusions in two steps. He first analyzes the moral meaning of proxy-consent in the therapeutic situation where all agree that it is allowed. He then applies the principles derived from this analysis to experimentation on the child in the non-therapeutic situation. Though I can readily agree with his conclusions, I cannot subscribe to the reasons he advances in their defense. And I believe that this disagreement is important because often in ethics, reasons for conclusions are more interesting than conclusions themselves, for if they are unsound they may, through logical extension,
contaminate even other areas of moral consideration.

McCormick argues that the reason why we can legitimately presume that an adult would decide in favor of experimentation which will be potentially therapeutic for himself is because he ought morally to do so. In other words, from the accepted proposition that one ought morally to try to save one’s own life in most situations, we can conclude to the proposition that a person would want to do so in those same situations.

McCormick then applies this thought to the non-therapeutic instance. He says that if we can discern that an incompetent adult or child ought morally to allow a non-therapeutic experiment to be performed on him/herself when there is no discernible risk, then we can presume that that person would want to consent to such an experiment.

Against Ramsey’s contention that to impute moral obligation upon the child is to falsely imply that it is a moral agent, McCormick replies that the use of ought-language need not be construed as implying either actual moral obligations or agency. It is simply a device or construction used to ascertain the reasonableness of our expectations and intentions. To apply such ought-language, he claims, is simply a way of pointing to the sociality inherent in all humans, a sociality shared by adults and children alike. If we say of an adult that he ought morally to supply certain benefits for others when this involves no discernible risk, we are not implicitly saying that they are moral agents possessing free will, but simply implying that they are social beings and that the quality of sociality bears certain moral responsibilities. Though a child does not share agency and free will, it does share this essential sociality. It may not be able to consciously experience this sociality or respond to its claims but we may do so for him, to the extent that it is reasonable.

Here I believe that McCormick is correct: the ought language as used in his argument need not be read as treating the child as an adult who has actual desires and freedom to choose. However, even though McCormick’s argument does not offend from that point of view, I will argue that his approach of determining what a person wants by first establishing oughts, and on the basis of this presuming consent, is untenable in general, whether it be applied to adults or to children.

McCormick’s argument can be schematized as follows:

- What A ought morally to do, A would (ceteris paribus) want to do.
- But A ought morally to do x.
- Therefore, A would (ceteris paribus), want to do x.

It is clear from his discussion that in speaking of wants in the first premises, McCormick is interpreting them to mean inclinations inherent in the essence of man as a social being. With Aquinas and other natural law theorists, he views these deep-seated wants (inclinations) as the ground of certain values, which values in turn ground certain moral “oughts”. These moral oughts are prescriptive re-writings of these deep-seated wants or inclinations; they are simply these wants presented in another form.
Natural law theory defends the existence of certain imperatives which all humans ought to embrace, because these imperatives are ultimately definitive of their own well-being, because they express in different words what each human being at the deepest level of his essence really desires. Moral oughts give voice to what humans most deeply want.

For McCormick, the reason why we can proceed to presume the consent of incompetent adults or children to be experimented on in therapeutic situations is because we know that they ought to choose to have well-designed experiments to be performed on them when these are the last hope for saving their life. We can know what they would want in such instances because we know that there is a strong moral imperative or “ought” for all humans to try to preserve their life. Similarly, one can presume that an incompetent adult or child would consent even to non-therapeutic experimentation when this does not entail a discernible risk or undue discomfort and at the same time affords significant benefit to others. Being a possessor of a social nature, this is what he/she ought to do, therefore it can be presumed that he/she would also want to do it.

This reasoning is not only unnecessarily complicated but, to my mind, also fallacious. For McCormick’s syllogism, if I have correctly construed it, appears to equivocate. It uses the word “want” in two different senses: to refer to essential inclinations in one mention (first premise) and to actual desires, or the presumption of such in the second mention (conclusion). But it is clear that these are two different realities or concepts, as we will show. The argument trades on the verbal similarity which exists between deep-seated wants and actual wants or willings and, as a result, commits what in logic is called the “fallacy of four terms”. It tries invalidly to deduce the presumption of an actual willing from a proposition announcing the presence of essential wants or inclinations which are revealed by a moral ought.

But the deduction of actual willings, or of the presumption thereof, from our essential inclinations, is contrary to our moral experience and offends our common moral understanding. Can one really determine what one would actually want in a situation from a perception of what one ought to do? Is it not as often the case that people do not desire to do what they ought? In other words, do not the actual desires of people or their decisions often conflict with what they are essentially inclined to, with their deepest wants? Is this not the very meaning of sinfulness? To point to a deep-seated want which all humans share is not, by the same token, to ascertain that this is what individual humans would actually want. Actual willings are often in disharmony with deep-seated wants.¹³

4. Presentation and Defense of the Present Author’s Position

It seems to me that if we can presume consent on the part of a child for an experiment benefitting himself, as all seem to allow, it is on much simpler grounds than McCormick’s considerations of essential inclinations and oughts. It is because self-preservation, statistically speaking, is
what the great majority of people desire most of the time. And it is this empirically verifiable behavioral constant which provides a simple and legitimate basis for a prediction of future activity and for a construction of a presumption of consent.

The same can be said for the case of the non-therapeutic experiment. It is a fact open to observation that most people act altruistically when an action seems important for the benefit of others and it involves minimal risk or discomfort to oneself. It is because empirical observation reveals the presence of this minimum of altruism in people of most ages and cultures that we can presume that an unconscious adult would, if conscious, decide, *ceteris paribus*, to undergo a mild experiment which gives promise of substantial benefit to his fellow humans. The same form of reasoning can be applied to the child in similar circumstances. The child is, after all, a human being and it can be presumed that it will have the same desires as other humans in terms of self-preservation and altruism. In sum, we know that people would want to act out of altruism to this minimal extent, not because we know that they morally ought to do so, but because by experience we know that they do constantly so act.

The attempt to move from moral oughts to what one would want tries to shed light upon a murky area from a source which is even murkier. Moral obligations are notoriously unclear, highly debated, and themselves call for justification. On the other hand, actual performances of people and a reading of their usual preferences is a much more straightforward and accessible matter.

We must keep in mind, too, Marx’s lesson that the morality of a society tends to mirror the interests of the power elite. In our society, it is clear from the moral acceptance of feticide that the ideal of pluralism upon which our country was founded has been narrowed to exclude the fetus and its presumed desires. The regnant morality of the adult population, which is clearly the power-elite in respect to children and the unborn, has already exploited the unborn for its own interests — interests which are, at times, admittedly quite important, but also for “interests on demand”. In such a libertarian moral climate, it is dangerous to try to derive conclusions regarding the volunteering of children from so-called “objective” moral premises. It is far safer to ask the members of the power group to consult their own desires and ask how they themselves would actually like to be handled by society in various experimental situations and from this, to presume the same desire in children.

My approach is safer because it reduces the legitimacy of experimentation to cases in which the common run of people would actually be willing to volunteer themselves. It is the lowest common denominator approach which goes along with what the general run of people would allow. It thus avoids an escalation of the presumption upon children to the heroic or supererogatory. It avoids, too, McCormick’s later propulsion of the obligation to volunteer for non-therapeutic experiments into the realm of social justice. To call it an obligation in justice seems excessive. This
can lead to an extrapolation of human sociality into higher and higher realms of obligation. The moral index of entering upon non-therapeutic experiment can, at most, be construed as a call upon one's altruism and charity. Consent for such experimentation can be presumed in children only to the extent to which such a degree of charity actually extends in the general population. The burden of the proof is with those who want to extend it further.

One question remains. If we allow, with McCormick, that a child can be presumed to undergo non-therapeutic experiments when there is no discernible risk, what shall we count as the absence of such a risk? Are even so-called "offensive touchings", mentioned above, off-limits as Ramsey contends? (Ramsey allows only such insignificant interventions as a buccal smear, weighings and the like). I think the answer to this once again lies in a statistical study. Questionnaires can be developed to ascertain what sorts of interventions adults would be willing to allow done upon themselves if they were in the "child" situation. These same types of things can then be presumed to be wanted also by the child in relevantly similar situations.

This may seem too individualistic an approach to McCormick, if I am to judge from some of his later remarks in response to criticisms by Ramsey. The question of the individual vs. society is always a delicate one in morality. It can not be decided in general and once and for all. One may have to shift emphasis from one side to the other of the scale depending on the subject matter at issue and the climate opinion in a culture. In the context presently under discussion, where we are dealing with defenseless and voiceless children, and in a climate which is utilitarian and anti-child as is our own, we would do best to lean toward favoring the individual. We are living in a technological society which has a bias toward the powerful, toward adults in full-fledged maturity, toward control, and toward the pre-eminence of conscious, experienced life. As Ralph Potter, the Harvard theologian, has insisted in speaking of abortion, the situation of our culture is such that we must take the safer path. We must not ask for whom the bell tolls. It tolls for all of us and for our children.

References

1. We accept that it is medically established that biological differences between adults and children are so marked that in some instances experimentation on adults cannot serve for advancement of pediatrics, and that therefore some experimentation on children is desirable from a medical point of view.


3. This general opinion is not universally held. Some liberal philosophers assimilate very young children to fetuses and feel that the same reasons which morally would permit abortion would also permit infanticide. Cf. Michael Tooley, "Abortion and Infanticide", *Philosophy and Public Affairs*, Vol. 2, 1972.


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10. McCormick interprets “discernible risk” as meaning “no realistic risk”. He finds unacceptable the HEW stance which allows experimentation even where some significant risk is present as long as “the potential benefit is significant and far outweighs that risk”. Cf. McCormick, op. cit., p. 5. McCormick also makes special allowance for institutionalized children. Because they are already a controlled group and are often physically and mentally disadvantaged, there exists a strong temptation to treat them as already less than fully human. This temptation must be guarded against by stricter norms than those regulating experimentation on normal children in ordinary situations. Moral permission for experiments upon them, which are neither therapeutic, diagnostic or prophylactic for the child-subject, should be given very rarely.
13. McCormick’s error is similar to that committed by R. M. Hare in The Language of Morals where he says that if a person assents sincerely to the proposition I ought to do x, it follows logically that that person wants to do x. The constant criticism of Hare is that he has not understood moral weakness or backsliding, which in theological ethics is equivalent to sinfulness.