

February 1979

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### Recommended Citation

Byrne, Robert H. (1979) "Non-Therapeutic Experimentation on Children: Moral Issues," *The Linacre Quarterly*: Vol. 46: No. 1, Article 9.

Available at: <http://epublications.marquette.edu/lnq/vol46/iss1/9>

# Non-Therapeutic Experimentation on Children: Moral Issues

Rev. Robert H. Byrne

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In the October, 1976 issue of *New Catholic World* magazine, Dr. Robert Cooke, vice chancellor for health services at the University of Wisconsin, stated that "consent" is the most significant medical-ethical issue society faces today.<sup>1</sup> From my own brief survey of medical-moral literature and three years of pastoral service which often included contact with families and physicians in hospital situations, I have to agree with Dr. Cooke. Consent that is "reasonably free" and "adequately" informed is the framework sought in any medical procedure, therapeutic or non-therapeutic, but in our present situation of a highly developed and specialized medical technology, whether this kind of consent is always possible has become problematic.

There are many aspects to the issue of consent, so in this paper I would like to focus on one aspect: consent in regard to non-therapeutic (experimental) procedures with children. This study points to one controversial problem in particular: presumed or "proxy" consent. When non-therapeutic procedures are considered with regard to children, the mentally retarded, or others judged incompetent to make their own decisions, it causes us to look more closely at what is involved in this type of presumed consent in any situation.

To my knowledge, one of the most helpful discussions of this issue can be presented by comparing the differing opinions published by Paul Ramsey<sup>2</sup> and Richard McCormick.<sup>3</sup> In this paper I will briefly present a summary of each position, the analysis given by William May in *The Linacre Quarterly*, and then present my own analysis and comment.

## Ramsey's Position

Ramsey's treatment of this issue of experimentation on children is based on one important principle: the relationship between a patient and a physician or between a subject and an investigator is a partnership of two human subjects. They are "joint adventurers" in a com-

mon cause. Consent expresses or establishes that relationship and the requirement of consent sustains it. Ramsey calls this "the Canon of Loyalty." This consent must be reasonably free and adequately informed to insure that a human subject is not being used as an object by another. Ramsey admits only one exception to this general requirement: in cases where persons are in extreme danger and cannot themselves give explicit consent, consent may properly be assumed or implied. The doctor is in the special position of being able to answer that need so that presumed consent does not do violence to the dignity of that person as a human subject.

Experimentation, like therapy, is a voluntary association of persons in a common cause and this association can only be established and expressed by the requirement of informed and free consent. In regard to the situation of medical experimentation on children or incompetents, Ramsey states his position clearly:

Children who cannot give a mature or informed consent should not be made the subjects of medical experimentation unless, other remedies having failed to relieve their grave illness, it is reasonable to believe that the administration of a drug yet untested or insufficiently tested on human beings, or the performance of an untried operation, may further the patient's own recovery.<sup>4</sup>

The conclusion for non-therapeutic medical experimentation on children is clear: when there is no possible relation to the child's recovery, a child is not to be made a mere object in medical experimentation for the sake of good to come. To even attempt to consent for such experimentation on behalf of a child is "to treat a child as not a child." It would be to treat a child as an adult who has consented to make himself a "joint adventurer in the common cause of medical research."<sup>5</sup> Anticipating the argument that consent could be presumed on the part of the child, Ramsey states quite bluntly: "If the grounds for this are alleged to be the presumptive or implied consent of the child, that must simply be characterized as a violent and a false presumption."<sup>6</sup>

Non-therapeutic experimentation must be based on true consent if it is to be a human enterprise and since children cannot give true consent, they cannot be subjected to this type of experimentation. Ramsey calls this our canon of loyalty (as adults) to children. When a child becomes an adult, he can volunteer for such experiments, but no one can volunteer a child or anyone else for non-therapeutic medical experimentation.

Finally, Ramsey looks at Anglo-American law and notes that protection is given to persons from harmful invasion of the body without proper consent, and from unconsented touching, even if no harm is done. This latter situation of non-harmful touching involves freedom from coercion to the will of another and wrongs another by doing

something to him without his consent. Ramsey concludes that children are protected by those same laws, even from "offensive touching" which is not physically harmful.

In summary, to bring a child within the ambit of medical investigation requires: 1) some relation to the child's own treatment, and 2) informed consent on the part of the parent or guardian. The consent on the part of the parent or guardian concerns the evaluation of the hazards to the child involved with using an experimental procedure for therapeutic purposes. It can be noted that Ramsey criticizes the Ethical Guidelines for Clinical Investigation prepared by the American Medical Association for not meeting these standards for proxy consent.

### McCormick's Position

McCormick examines the situation where proxy (meaning "presumed") consent is considered legitimate to see if a guideline can be established for applying to the more problematic situation of non-therapeutic experimentation. Presumed consent is considered legitimate in the therapeutic situation where procedures are intended to be of benefit to the health and life of the subject who is incapable of giving consent for himself. The parents or guardians can give consent because the incapable subject can reasonably be presumed to give consent if he were able to do so.

The reasonableness of this presumption is due to the fact that life and health are real human goods and all men have an obligation to pursue the human good because they are men. Thus McCormick argues that parental consent is morally legitimate where therapy on the child is involved because we know that life and health are goods for the child, that he would choose them because he ought to choose the good of life as long as this life remains, all things considered, a human good. Thus it is reasonable to presume that the child would consent to the procedure in question because he ought to do so.

On the basis of this analysis of the therapeutic situation, McCormick moves to the situation where non-therapeutic experimental procedures are involved. He first asks: are there other things which the child ought, as a human being, to choose precisely insofar as they are goods definitive of his own well-being? He answers that we are social beings and the goods that define our growth are goods that reside also in others, so that it can be good for one to pursue and support this good in others. Therefore when it factually is good, we may say that one *ought* to consent to such a procedure. Finally, if this "ought" is true of all of us to a point and within limits, it is no less true of the child. He would choose to consent to these non-therapeutic procedures because he, as a human person, ought to do so.

As I understand McCormick's argumentation, there are some non-therapeutic procedures that involve no discernible risk, discomfort, or inconvenience, yet promise genuine hope for general benefit. We all have a general responsibility to help in the process of controlling diseases and maintaining health. Since it is good that all of us as human beings share in these experiments, and hence good that we ought to do so, then "a presumption of consent where children are involved is reasonable and proxy consent becomes legitimate."<sup>7</sup>

McCormick is quick to stress that this presumed obligation on the part of the child is true only up to a point and within limits: experiments that would involve no discernible risks, no notable pain, no notable inconvenience, and yet hold promise of a considerable benefit to others. At the same time, there can be no question of presuming consent in other situations where risk or discomfort might be involved, even though there would seem to be great benefit to be gained for others. This kind of "consequentialist calculus" would go beyond the boundary of reasonably presumed consent.

In summary, McCormick argues that from the situation of legitimate proxy consent in situations of therapeutic experimental procedures on children, one can infer moral justification of proxy consent in purely experimental situations under very limited conditions.

#### May's Evaluation of Ramsey and McCormick

In his article, William May specifically examines McCormick's position in the light of Ramsey's analysis, and then adds a further helpful element.<sup>8</sup> According to May, any "proxy" consent when a person other than the subject of the procedure is authorizing that person's participation in it is false consent based on false presumption. Consent is a human activity and requires knowledge and freedom of choice in order to exist. Children or mentally incompetent or unconscious persons (adult) are not capable of knowledge or freedom of choice, so they cannot be classed as "moral agents" who are capable of giving consent.

On this basis, May criticizes McCormick's analysis of the therapeutic situation with regard to children. Parents cannot presume consent on the part of the child on the basis that he ought to so choose if he could because the child is not a moral agent and is not subject to moral obligations. The reason justifying medical treatment of children or any other victims is the obligation on the parents of medical personnel to that person, not a presumed consent on the part of the person himself. So May feels that any "proxy" consent as presumed consent is false consent. It is consent *by the parents* for certain means to be used in order to fulfill their own obligation to help their child in his need, but not a presumption of the consent of the child. May

therefore agrees with Ramsey's analysis: children are not to be made subject to non-therapeutic experimentation, even to the minimum of offensive touching.

### Evaluation

What emerges from all this is that there are two different issues in the discussion of non-therapeutic experimentation on children. First, there is the question of "presumed consent" and secondly, there is the matter of the "canon of loyalty" with regard to children. Since they are different issues, it is important that they be kept distinct because the conclusions drawn from them are not the same conclusions.

*The question of presumed consent:* In regard to presumed consent, both Ramsey and McCormick point to the crucial importance of consent, but the special situation of children brings up some difficulties in regard to any kind of "presumed" consent. As I first understood it, presumed consent required a reasonable basis for the presumption. In the case of an adult, the reasonable basis referred to the will that the patient had shown by his previous actions and on that basis, the next of kin could "presume" his consent in regard to a certain medical procedure. However, after examining this issue in the case of children, I have to conclude that presumed consent, whether involving an unconscious adult, a mentally retarded person, or a child is fiction rather than fact. I agree with May that the real basis for allowing therapeutic medical procedures is the responsibility of the parents, guardians, next of kin, or the physician to the person in need. It is not a presumption at all because the author of the consent is not the patient.

The content of the consent given in such a situation concerns the type of treatment that is to be given, especially in regard to relatively extraordinary means. In the case of an unconscious adult, the next of kin can make a "presumption" of what the patient would want done if he were conscious because of what they had seen him choose in the past. They saw him act in different situations and this knowledge can help them make the decision of what means should be used, but this is only part of their obligation to that person. This is not a presumption of an "ought" on the part of the patient to use ordinary means to preserve his life, but a recognition that other persons have obligations to see that ordinary means are used to help this person in need. Relatively extraordinary means may be used and that judgment, I think, should be based on a knowledge of what that patient, if an adult, had shown by his choices in the past.

In the situation involving a child, there is a real difference from the situation described above because the child has no history as a moral agent. There is no basis from past actions to make any kind of presumption of what the child would want. The parents, then, must

decide on the basis of their own obligation and judgment whether relatively extraordinary means should be used. The real basis of consent is the judgment of the parents and that consent must be reasonably free and adequately informed. This type of reasoning would seem to be supported in legal practice where the court orders the use of relatively ordinary means (e.g., a blood transfusion) to treat a child in danger of death when the parents will not give their consent for the procedure. The state is acting from its obligation to its citizens and not from any presumption on the part of the child.

In situations involving non-therapeutic experimental procedures, I would conclude that "presumed" consent is not a valid category in regard to adults or children. Such procedures should be allowed for adults only if they have left prior authorization or consent in the form of a will. As for children, I agree with Ramsey and May that non-therapeutic experimental procedures are not to be used, but I would add one qualification. This conclusion brings up the second issue referred to above: the canon of loyalty to children.

*The canon of loyalty to children:* This is a very important obligation, but a very difficult one to translate into practice. The child has rights as a human person, but he is in no position to defend himself, so he needs parents or guardians to defend them. Yet in the defense of those rights, the child can make some contribution to how those rights are understood by the parent or guardian. For example, in cases where custody of a child is in question because of a divorce, if the child is old enough to express himself, the judge will often talk to the child to try to determine with which parent the child would be most happy to live. The final decision depends on the judge, not on the wishes of the child, yet those wishes can be one element contributing to his judgment.

I think this type of reasoning can also apply to a situation involving what Ramsey calls the "inviolability of the body." Law does protect the body of the individual from invasion of another, but when the situation of invasion involves an adult, the law is not applicable unless the person makes a complaint. In cases of non-harmful touching, the complaint is not presumed but must be expressed by the person. In the case of a child, parents and guardians can make such a complaint, but in order to be reasonable, their judgment must be based on some input from the child. A child usually makes it clear whether he wants to be touched or not. So I do not think that children are being treated as objects in experimental situations where there is no discernible risk or undue discomfort with the consent of the parents or guardians on the grounds that parents can allow an adult to touch their child when the child by his own actions obviously does not object. The child has not given the consent and has not made the judgment, but has given some expression or input to the parents who give the consent.

In conclusion, I agree with Ramsey and May in regard to the issue of presumed consent, but not with the extent of their conclusion. I think that when simple experimental procedures involve no discernible risk or undue discomfort, yet offer hope for reasonable benefit for others, parents can give their consent for such procedures, taking account of the input they receive from the child. Thus I agree with McCormick's conclusion about non-harmful experimentation with children, but not with his lines of argument. This paper began with the recognition that consent is a difficult issue and after struggling with the issues pointed up with regard to children, I appreciate the difficulties even more.

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