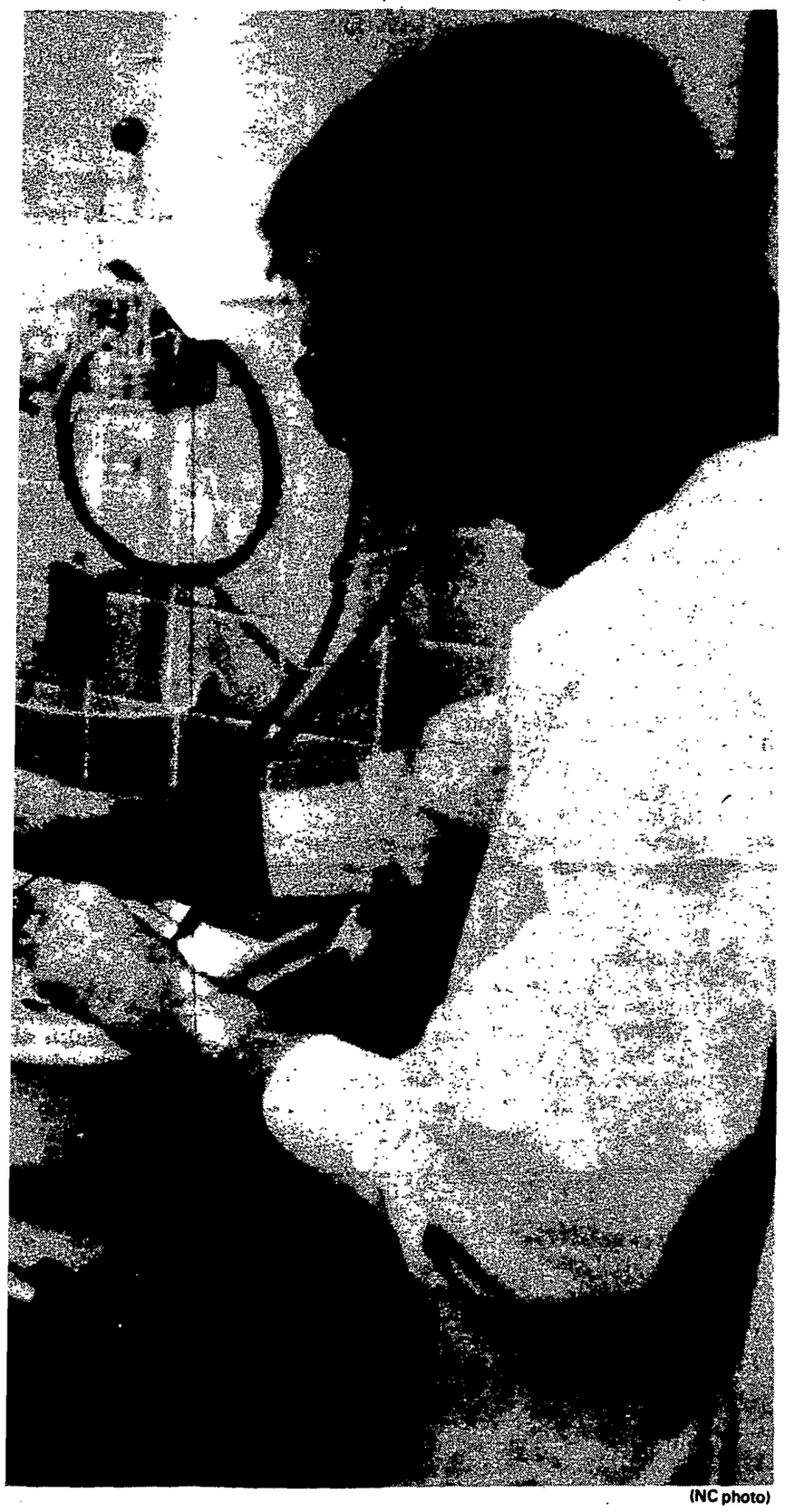
A Constant Ethic

ı and the Sanctity of Life



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rapeutic" and "non-therapeutic" research, and between "consenting" and "unconsenting" subjects. Both distinctions are based on respect for the inviolability of each individual human being. "Non-therapeutic" research is more difficult to justify than "therapeutic" interventions because in the former case one runs the risk of using the individual merely as a means to some larger social good. This risk turns into reality when the subject has not given informed consent or is incapable of giving such consent. Since the human subject has an inherent right to life and bodily integrity, a researcher has no right to risk harm to this person for the benefit of mankind — unless that person freely volunteers to undergo such risk to serve others.

Catholic morality recognizes that this kind of service, like the willingness to become an organ donor, can be genuine expression of Christian charity. It also recognizes certain moral limits.

Because life ultimately belongs to its Creator, we are called to careful and responsible stewardship over our own lives.

The most difficult problems in this area, however, involve subjects, such as children, who are incapable of informed consent. It is generally agreed that parents or guardians can give informed consent on behalf of their child for beneficial medical treatment, even when the treatment may be experimental. But can parents consent to research that imposes risks on their child for the benefit of others?

Until quite recently, that question would have been answered almost unanimously in the negative. Western codes of medical ethics, expecially those formulated in the wake of the Nuremberg trials, insist on the inviolability of the unconsenting human subject. In 1964, for example, Dr. Ross G. Mitchell spoke for many when he said that "an experiment is permissible provided that the risk does not exceed the ordinary risks of daily living . . . Experiments carrying a greater risk may, of course, be permissible if an ill child is expected to benefit directly. I believe it is dangerous to suggest that an experiment which might otherwise be unjustifiable is justified because it is for the common good."

This approach has been endorsed by ethicists representing all three strands of the Judeo-Christian moral tradition. Perhaps the point has been expressed most forcefully by Methodist theologian Paul Ramsey of Princeton University. Ramsey approaches the issue in terms of the special covenant between a child and a parent committed to the child's welfare: "Faithfulness to a child," he points out, "includes the requirement that we do not inflict pain or risk in addition to those of ordinary daily living. But fidelity to a human child also includes never treating him as a means only, but also as an end."

Speaking from a Roman Catholic perspective, Rev. Richard McCormick of the Kennedy Institute of Bioethics agrees: "Where children are concerned, proxy consent is legitimate when the experimentation involves no discernible risks, discomforts, or inconvenience — in human judgment." In 1975 Father McCormick urged the Commission for the Protection of Human Subjects (without success) to apply this principle to the unborn child.

Rabbi Seymour Siegel, Professor of Theology and Ethics at Jewish Theological Seminary in New York, reached a similar conclusion in his 1975 testimony before the Commission: "Experiments for the 'good of medicine' or for the sake of the 'progress of knowledge' are not automatically legitimated, if they cause harm to people now, because someone in the future might benefit. What comes in the future is what the Talmudic literature calls 'the secrets of the Almighty.' This does not mean that we have no responsibility toward the future. However, we have a greater responsibility to those who are now in our care."

American law has reinforced this ethical consensus by decreeing that parents do not have the right to expose their children to significant risk to advance medical knowledge. In 1968, Justice Warren Burger (then serving on the D.C. Court of Appeals) reflected this legal tradition when he said that "no adult has the legal power to consent to experiments on an infant unless the treatment for the benefit of the infant."

It is clear that this tradition is not being consistently applied to the unborn child and premature infant, at least when abortion is involved. But the ethical principles recounted here also raise questions about other forms of experimentation.

With new advances in recombinant DNA research, pressure has grown in the scientific community to allow genetic experiments on embryos, fertilized *in vitro*. Three considerations make this debate slightly different from the debate about experimentation on the child in the womb.

First, the embryo is completely separate from the mother. Thus there is no possible conflict between the child's life and any alleged "right of privacy" of the mother. But it also seems to invite some researchers to treat the newly conceived embryo as just another lab specimen — one that can be frozen for later use or even discarded if imperfect.

Second, this debate primarily concerns embryos less than two weeks old, who some ethicists see as not deserving full protection because of speculations about the absence of human "individuation" at this stage. In August 1984, two Catholic theologians responded to this argument in Congressional testimony on embryo experimentation. Rev. Donald McCarthy of the Pope John XXIII Medical-Moral Research and Education Center cited Dr. Robert Edwards, himself a leading proponent of experimentation, as saying that the embryo is "a microscopic human being — one in its very earliest stages of development." Father McCarthy urged full protection of the human embryo from fertilization because it is clearly a distinct member of the human species whose development "culminates in an adult human being by a continuous dynamic growth if only nourishment and a favorable environment are provided."

Finally, this form of experimentation poses risks of an entirely new order to the subject. In most human research one deals with risk of pain or injury. With genetic modification of the early embryo we confront the risk of depriving children of membership in the human species. This may have been a factor in Pope John Paul II's unusually forceful words in a speech to the Pontifical Academy of Sciences in October 1982. "I condemn, in the most explicit and formal way, experimental manipulations of the human embryo, since the human being, from conception to death, cannot be exploited for any purpose whatsoever."

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The transplants performed on "Baby Fae," Barney Clark and William Schroeder pose a less fundamental problem insofar as their treatment was designed to benefit these patients as individuals. While some people's sensitivities were offended by the thought of transplanting a baboon heart into a human child, or replacing the human heart with a mechanical pump, Catholic theologians do not see this as a moral problem in and of itself. The ethical question is: Were these treatments so experimental that they could be foreseen as offering no reasonable hope of benefit to the particular patient involved?

This question has been raised most frequently regarding the "Baby Fae" case. Some critics of this ultimately unsuccessful experiment believe either that the child's parents were essentially consenting to an experiment they knew had no real chance of saving their child, or that their consent was not genuine because they had been given false hope regarding the treatment's effectiveness.

Regarding Barney Clark and William Schroeder, the first human recipients of the artificial heart, there is less disagreement because it seems clear they exposed themselves to the risk of an experimental procedure after giving informed consent and considerifng the risks and benefits of other proposed therapies.

These and other applications of the basic moral principles regarding human experimentation will continue to exercise the ingenuity and discernment of all of us, not only of professional ethicists. But there is no reason to think the principles themselves are any less useful or relevant today than they were in times when medical science seemed less complex.

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