Dilemmas of Experimentation on Children

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recommended and being awarded legal recognition, these schizophrenic patients are placed in a most difficult situation. They are genuinely, though psychotically, concerned with their gender identity and indeed some do castrate or mutilate themselves. How does one now deal with their request for a “sex-change” operation? We now have the paradoxical situation that if an individual is really mentally disturbed over his gender identity, it would be bad medical practice to subject him or her to reconstructive surgery, but an individual who is not mentally ill can have the operation on psychiatric grounds.

Perhaps it is not so strange when one considers that upwards of 45% of all legal abortions are done on psychiatric grounds, whereas it has been adequately demonstrated that those who are at greatest risk in terms of psychiatric sequelae of abortion, are those with a previous history of mental illness.

I have only pointed out some of the nonsense. Doctors must use their influence with the public and politicians to stop it.

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Paul F. Cavanaugh, Jr.

This paper was presented at the Northeast Undergraduate Conference on Bioethics, held at the University of Massachusetts at Amherst on April 9, 1976.

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Without human experimentation, modern medicine, as we know it today, would not exist. Along with being essential to progress, it can also create a dangerous path for naive and unprotected individuals. Even with new laws and medical declarations, e.g. Declaration of Helsinki, the burden of deciding whether specific experimentation is ethically and morally sound is still much in the hands of the researcher. This predicament is not the total fault of the researchers, but is caused by the tremendous increase in technology which has surged far above and beyond the understanding of the majority of individuals in our society during this century. Society as a whole has become awed and mystified by this technology, so much so that it has retrograded into a state of ignorance.

How can we begin to judge something which is beyond our own comprehension? Should we leave the judgment to the scientists, the very creators of this vast amount of technology? To leave the decision of the morality of using such technology totally to the scientists would certainly be self-defeating. The only logical solution to this question is given in The New Biology: What Price Relieving Man's Estate, by L. R. Kass, in which he states that the only hope is public education as to the broad meanings of science and more responsible scientists. A definite trend towards this goal can be seen growing today; whether it is reached remains our responsibility. Our physical, mental and social well-being and that of future generations rests in achieving this goal in order that we may intelligently develop technology for the benefit of society and the individual.

In the field of medical research, the medical community must be guided by a definite set of ethics which has been attempted many times. This necessitates a definition of ethics and then an interpretation of these ethics in medicine. A definition of ethics acquired by this author in a series of fifteen seminars in medical and moral problems in modern medicine at Boston College with a group of twenty-five participants, each with varying backgrounds and beliefs, is as follows: “Ethics are a dynamic set of values which are learned, reflected and experienced. They are applied to life situations and acted upon to govern and protect
the individual and society's freedom for self-fulfillment."

This presentation will incorporate this theme of ethics as a framework in dealing with the dilemmas of experimentation on children, both therapeutic and non-therapeutic. As a group of people, children are unable to control their future and are literally at the mercy of others.

At one end of the spectrum lies the area of therapeutic experimentation. Frequently, individuals enter the world in an abnormal state, psychologically or physically, or both. Some of these children can be given the precious gift of life by established medical techniques, most developed by never-give-in physicians and researchers. For others, however, medical technology offers little or no hope at the present time. Should researchers continue to experiment with new concepts which are the only hope for these children, or should they and the parents of these children deny them the chance, however slim, to live by a halt in experimentation? Who decides? On what basis should a decision be made, legal, social, or religious?

In making such a decision, should one group of people have more or less influence on the child's future? These decisions involve, in most cases, a matter of life or death. In the majority of cases religion becomes a strong basis for the decision, along with one's own personal set of ethics. The legal and social aspects also influence the decision greatly.

As in the case of newborn infants, the decision rests almost entirely in the hands of the parents. They are forced to make the decision of allowing their seemingly hopeless child to die or to permit the medical staff to experiment with new ideas or concepts to keep the child alive. This type of decision-making occurs, for example, in the case of children born with the defect spina bifida. Many of these infants are labeled hopeless cases. But what is hopeless? The hopeless case of ten years ago may be the hopeful case of today. In making these judgments, social and economic factors are placed upon the parents. People with such children become stigmatized within society, bearing the label of being "the parents with the abnormal child." Many parents cope with this burden quite well, but others do not and still others eliminate it from the beginning. The question now is not the quality of life of the child, but the quality of life of the parents. This thought should never enter into their final verdict. All emphasis should be placed on allowing the child to live to the fullest, for it is very easy to condemn a class of individuals with no voice of their own. This is where the law must come in, to guarantee their rights as individuals.

Two Main Issues

In summary, two main issues are confronted: the sanctity of life and normalcy. Every life has value, feelings and a right to exist and there should be no exceptions, for example, in the case of the unborn, the retarded and seriously ill. We must strive to offer the opportunity for these individuals to live with us and to live as fulfilling a life as possible.

As was previously stated, some are denied this right, or would be denied this right by some because of their so-called 'abnormality.' In an article written by E. A. Murphy, "Scientific Viewpoint on Normalcy," he describes the double set of standards which we sometimes attempt to formulate. He sets out to prove and does, by using a tremendous amount of factual, statistical evidence, that in science there is no normalcy. Who is to say that he or she, as an individual, is normal? The standard on which an individual bases his or her decision can lead to an enormously large difference in opinion. Some people, for instance, believe that children with serious birth defects are not entitled to the same basic rights to life as any other individual. Such a belief could easily lead into other drastic consequences, as seen in an article by Leo Alexander, "A Medical Science Under Dictatorship." The author tells how the so-called abnormal individuals of German society under Nazi rule were quickly exterminated. Hopefully, no attempt to normalize a society will ever be thought of again. Certainly, trying to judge who should be given a chance to live and who should not is a terrifying step in this direction. It is, therefore, my belief that therapeutic pediatric research must continue, for it is the only hope for children with serious illness, with no cure at the present time. Also, it will prevent the stagnation of medical technology, which someday will find a cure. The length of time until cures will be discovered cannot be known. For the seriously ill child, there is at least some hope. A quote from Eleanor Roosevelt sums up this belief:

I don't know whether I believe in a future life, but I believe that all that you go through here must have some reason. And there must be some 'going on.' How exactly that happens I've never been able to decide. There is a future and that's sure of. But how, that I don't know. And I came to feel that it really didn't matter that much, because whatever the future held you'd have to face it when you came to it, just as whatever life holds you have to face it in exactly the same way. And the important thing was that you never let down doing the best that you were able to do - it might be poor because you might not have much within you to give, or to help other people with or to live your life with. But as long as you did the very best that you were able to do then that was what you were put here to do and that was what you were accomplishing by being here."

Conversely, a dilemma in the field of non-therapeutic experimentation on children arises in genetic research, behavior control and modification, to name a few. Here the rights of confiden-
tiality informed consent of the children are challenged.

Willowbrook Case

This is exemplified in the historic Willowbrook case, which took place in the 1950's in this country. It involved an experiment where retarded children were fed feces infected with hepatitis in the hope of producing a suitable vaccine for hepatitis. Also, there have been experiments in behavior modification of children using drugs, which have taken place in some schools within this country and experiments in genetic research and screening with the fearful possibility of eugenics lurking on the horizon. Thus, children have been labeled hyperactive, or as having genetic defects, etc. Their complete medical histories are known to their entire family before they even reach adulthood in many cases. They then grow up to face a sometimes hostile society, which shuns defects or abnormalities. For example, with all the publicity about the implications of persons having an extra Y chromosome, such a person could view himself or herself as a deviant, an outcast of society. Not only does the individual know this, but many of his or her friends have knowledge of this from the breach of confidentiality which may have occurred in childhood. Once again we see the dilemma of seeking a true scientific definition of normalcy in humankind.

Definitely these types of research may impede a child's struggle for self-fulfillment and happiness in the future, for experiments such as these involve risks, psychological or physical. They more often than not offer little or no direct benefit to the people being experimented upon in contrast to therapeutic experiments. Non-therapeutic experiments usually are more beneficial to the career of the researcher. In no instance, however, should a researcher place his or her research above the mental, physical and social well-being of the volunteers.

The necessity arises for a decision on whether it is better to strive for purer scientific knowledge and disregard the individual altogether, or actually ask ourselves if we really have to know things such as at Willowbrook, which only experimentation can tell us. Does the entire future of mankind depend solely upon unlocking such mysteries of life?

Review boards are needed with well-informed and educated citizens from different segments of society, not just the scientific establishment, in order to reach an honest, unbiased decision. These questions of who should make such decisions, no doubt, lend themselves to another area of discussion.

Once an experiment is designed and approved, the job of the scientist is to find enough courageous individuals. When adults are needed, there are often problems, even though most adults have enough knowledge and foresight to comprehend exactly into what they are getting themselves. However, when children volunteer, the dilemmas are magnified considerably. For example, is their consent truly informed consent? Most definitely not! A scientist dedicated solely to discovering new scientific knowledge could easily convince anyone, even himself or herself, that the research he or she is carrying out is vital to humanity. This has occurred in all areas of science, not just in medical research. A naive individual stands no chance against such a scientist. Also, if the research is truly for the benefit of humanity, why don't researchers allow their own children to participate if they believe so strongly in their work? Maybe some form of the Golden Rule should be implemented.

When a child does volunteer, what motivates him or her to do this? It could be to please his or her parents or the experimenter, for personal prestige, or some other factor. For whatever reason the child may be motivated, it does not warrant placing this person’s well-being in jeopardy.

Parental Influence

The parents or guardians have a significant influence in this decision. What parents would allow their children to risk their lives? A child can be influenced very easily by his or her parents. As a preliminary, therefore, the child’s family background should be carefully studied to search for the true reason why the parents have volunteered their child. Could it possibly be from hate and the hope of legally getting rid of the child for economic or social reasons? Many other factors may also lead to a similar situation. Thus, there is the creation of another complicated, infinite set of dilemmas.

Non-therapeutic experimentation stands on a hideous foundation. Why do we have to know whether a child has an unnoticeable genetic defect, or other so-called abnormality? Why should we take these unnecessary risks? Conversely, in regard to therapeutic experimentation, there is no future without it at times.

I have presented but a few dilemmas of experimentation on children which can be applied to adults as well. With each new proposed experiment these questions should be asked. The responsibility rests with us to do, not what is scientifically sound, but more importantly, to do what is ethically sound. The rights to life, liberty and happiness of our generation must be upheld. Our every decision must be guided by a definite set of ethics in the area of non-therapeutic experimentation, otherwise research may fall prey to pragmatism, with no definite goal or purpose. This can then lead to the use of experimentation for personal, as well as political gains. We must protect all children so that members of future generations will look back at our generation with respect.

REFERENCE