2/14/77

MARC BIO Ethics Seminar

I appreciate the opportunity to participate in this important pioneering seminar. It is a chance to do the impossible. It is impossible for me to expend 30 minutes in discussing the law and amniocentesis, abortion, vital organ transplant, legal death in Minnesota, euthanasia, use of heroic measures to prolong life, infanticide and child abuse.

Mel Duncan awarded me this assignment and I feel like the whale that is most endangered; namely, the one that spouts too much.

Law, government and medicine have profoundly impacted upon mentally retarded citizens during the past 27 years. This impact may be even greater during the next 27 years.

Today it is popular to fear Hitler-like infanticide and euthanasia, the Dr. Sackett's and other misguided professionals and laymen who advocate active or passive euthanasia for mentally retarded persons. Although these fears are justified and deserve our strong resistance thereto, I am genuinely optimistic about their ultimate failure. OF THE DOCTOR SACKETTS

I am not so certain that we do not have more to fear from an over reaction to Hitler and Sackett and an increasing unwarranted over protection of retarded citizens by well-intentioned governments', professionals' and courts' interference, involvement and rules and regulations which may be a greater risk to the retarded citizen's right to life, liberty and the pursuit of happiness.

I

Amniocentesis

Amniocentesis is a process of withdrawing fluid from the amniotic cavity. It is sometimes called genetic needle biopsy. One purpose is the early detection of potential birth defects. I have found no cases holding it to be unlawful. Should it be

lawful? Should it be encouraged from a medical, moral or ethical point of view?

Arguments for Encouragement and Expansion of Amniocenesis:

1. Medical risk is minimal. Canadian Medical Research Council Report (NWN Oct. 20, '75, p. 17) U. S. Study (MWN 7/12, p. 72)
2. Can save lives by intra uterine treatment of some of the inborn errors of metabolism.
3. Enhances future potential for saving more lives.
4. Enhances knowledge of neonatalogy.
5. Can assist in the energetic treatment of post natal treatment of known genetic disorders. (See Life and Meaning for the Handicapped - Menolascino 1/22/77)
6. Provides reassurance to anxious high-risk mothers when test results are negative.
7. Gives the mother the option of abortion or non-abortion of the fetus when the test results are positive.

Arguments Against Use of Amniocenesis:

1. Some risk of injury to or death of fetus.
2. May reinforce parental rejection of retarded child if parents know its birth could have been prevented.
3. May absorb funds which would otherwise be used for treatment of the new born defective
4. May increase abandonment of child by parents by omitting to secure such diagnosis before birth.
5. May enhance use of abortion and euthanasia.
6. May produce adverse effect upon another defective child if he knows amniocentesis and abortion resulted to his unborn sibling. See "Attitudes Toward Defective Newborns", by John Fletcher, Hastings Center Studies January, 1974, Vol. 2, No. 1.

II

Abortion

Is abortion lawful in Minnesota? Yes, under certain circumstances.

Authorities - Roe v. Wade 410 U. S. 113

M.S.A. 145.411 - M.S.A. 145.423

Hodgson v. Anderson D.C. 1974, 378 F. Supp. 1008, Appeal Dismissed 95 S.Ct. 819

State v. Hodgson - 1973, 295 Minn. 294, 204 N.W. 2d 199

Doe v. Randall - D.C. 1970, 314 F. Supp. 32, Affirmed 91 S.Ct. 1656, 402 U.S. 967, 29 L.Ed. 132

State v. Hultgren - 1973, 295 Minn. 299, 204 N.W. 2d 197

In Roe v. Wade, the United States Supreme Court outlined the constitutional limits of a state's authority to regulate abortions. During the first trimester of pregnancy the state has no authority to interfere in the abortion decision, that decision must be left to the judgment of the woman and her physician. After the first trimester and until fetal viability, the state has authority to regulate abortions to the extent necessary to protect maternal health. After viability the state has absolute authority to proscribe abortions except where it is necessary for the preservation of the life or health of the mother. The U. S. Supreme Court obscured the exact point of viability, stating that it is usually placed at about 7 months (28 weeks) but may occur earlier, even at 24 weeks.

The Minnesota Statute gave the state the absolute right to regulate abortion after 20 weeks of pregnancy.

In Hodgson v. Anderson, the U. S. District Court invalidated those provisions of the Minnesota Act which prohibits abortions after only 20 weeks. It also declared that any regulation promulgated by the State Board of Health affecting an abortion in the first trimester were invalid. It also found the Board's regulations

affecting abortion during the second trimester were invalid since they tended to discourage the establishment and operation of abortion facilities and inhibited the abortion decision making process. Finally the Court held that the Minnesota Act which provides "no person and no hospital or institution shall be coerced or held liable or discriminated against because of a refusal to perform, accommodate, assist or submit to an abortion for any reason", was invalid as applied to "institutions clothed with state action" the court said "to hold otherwise would have allowed the state to severely restrict the availability of hospital facilities for abortions and thus effectively interfere with the abortion decision".

In Roe v. Ward the U. S. Supreme Court also held that the right to privacy encompasses a woman's decision whether or not to terminate her pregnancy; that a woman's right to terminate her pregnancy is not absolute and may to some extent be limited by the state's legitimate interest in safeguarding the woman's health, in making proper medical standards and in protecting potential human life; that the unborn are not included within the definition of "person" as used in the Fourteenth Amendment.

The abortion issue continues to be hotly debated. Opponents argue that the legalization of abortion has produced the slippery slope of degradation of human life; that it is murder; that it enhances the chance for legalization of the extermination of newborn mentally retarded children. Proponents argue that the right of the mother to abort is paramount to the non-existent right of the unborn fetus to life; that abortion in some cases may prevent mental retardation, a goal almost universally accepted; that such prevention does not in any respect degrade mentally retarded persons who have been born; that increased prevention may result in more funds being available to improve the quality of life for the living retarded person.

Some interesting issues are:

1. Should it be a crime for a licensed physician to perform or a mother to consent to an abortion?

2. Should a doctor, hospital and mother be civilly liable to the state or to the mother's husband, son or daughter for the wrongful death of the unborn fetus?

3. Should a "normal" or retarded woman be forced to have a baby she does not want, lose her hard found job, give up her baby because she can't care for it, lose her apartment for non-payment of rent, and be forced on welfare?

4. Should parents be forced to have 2 or 3 retarded children as opposed to having an abortion?

5. Should parents be forced to have 4 children rather than 3?

6. Should a single woman attending college or pursuing a career be forced to risk loss of her life, her college or her career.

III

Vital Organ Transplants

My research has been inadequate. In 1963 a Minnesota Court ruled that a young man, age 22, who was a resident of the F. S. H., could not be permitted to donate a kidney to his sister, "because the decision could not be legally his own". In Kentucky, a more recent case permitted a mentally retarded young adult to donate one of his kidneys to a younger brother.

Issue: Should a retarded person have the right to donate certain tissue or organs provided certain safeguards are met? What safeguards should be instituted?

I will suggest that a retarded person should have such right provided:

a) No transplant should be done over his objection.

b) No transplant should be done because the donor was ~~related~~ RETARDED or because parents, relative or guardian believed the retarded person's life or health were less precious than the donees.

c) The retarded donor's physical condition was thoroughly examined and it was found to a reasonable medical certainty that such a transplant would involve only a normal minimal risk of injury or death to the donor,

d) That to a reasonable medical certainty, the transplant would have a greater chance for success than failure,

e) That no such transplant should be done for research purposes only,

f) That the retarded person receive a thorough description of the risks involved and be given the opportunity to consent or refuse or that if he is incapable of understanding, that his parent or guardian has the opportunity to consent or refuse consent for him.

IV

Legal Death in Minnesota

Practically, in Minnesota, death occurs when a doctor says it has occurred. Some argue that death is the final and irreversible cessation of perceptible heartbeat and respiration, and that conversely, as long as any heartbeat or respiration can be perceived, either with or without artificial aids, and regardless of how the heartbeat and respiration are maintained, death has not occurred. Others argue that if there is an irreversible cessation of total brain function according to usual and customary standards of medical practice, the person shall be considered dead even though he can breathe and his heart beats solely by aid of the respirator.

Issue: When can the surgeon legally carve out the beating heart and the internist legally pull the plug on the respirator without being guilty of euthanasia or negligence and with full protection to the right to life of the patient and with effective transplantation of the vital organ from the deceased body of the donor to that of the living body of the donee?

At present there is one bill defining death introduced in the Minnesota Legislature; the AMA opposes a statutory definition

of death; the National Right To Life Committee opposes same; the ABA favors its proposal; the Minnesota Medical Association favors its proposal.

The ABA's definition is: "For all legal purposes, a human body with irreversible cessation of brain function, according to usual and customary standards of medical practice, shall be considered dead."

Brain death is an accepted medical opinion. It would appear to me that a statute legalizing the concept of brain death without setting forth the specific medical guideline for determining brain death makes sense and should not be delayed by virtue of unwarranted fear of the fact that some doctor could violate the standards of medical practice. I do not believe the retarded citizen has any more to fear from such legislation than the normal. Under none of the proposed definitions would Karen Quinlan be considered medically and legally dead for the reason that although her coma was concluded to be irreversible, there was not a finding that she had sustained an irreversible cessation of brain function.

V

Euthanasia and Infanticide--
Heroic Measures To Prolong Life

Webster's Seventh New Collegiate Dictionary defines euthanasia as the act or practice of killing individuals that are hopelessly sick or injured for reasons of mercy.

Taber's Cyclopedic Medical Dictionary, Edition 10, defines it as 1. an easy death, 2. the proposed practice of ending of life in case of incurable disease.

I believe there are many other definitions and much confusion over what is or is not, what should or should not be called euthanasia. There is also much disagreement over the terms voluntary and involuntary, active, passive or direct or indirect euthanasia.

Infanticide is the killing of an infant.

Before discussing this issue I commend for your reading the following:

1. Dr. F. Menolascino's 1-22-77 Speech, Life and Meaning for the Handicapped;
2. Right to Life, Involuntary Pediatric Euthanasia by Harvy D. Stevens and Richard H. Conn;
3. Euthanasia As a Form of Medical Management by Dennis J. Horan;
4. Attitude Toward Defective Newborns, by John Fletcher, Hastings Center Studies, January 1974, Volume 2, No. 1;
5. Which Infant Should Live? Who Should Decide, by Beverly Kelsey;
6. Moral and Ethical Dilemmas in the Special Care Nursery, by Duff & Campbell, The New England Journal of Medicine, Volume 289, No. 17, Oct. 1973, pp.890-894

The Horrors of Hitler - 1977

1. Dr. Sackett once recommended withholding penicillin treatment for upper respiratory illness in Downes Syndrome children.

   He advocated permitting them to die for two prime reasons - a) cost benefit to Floridian Society and b) Downes Syndrome children were somehow sub-human or low quality of life persons.

2. In John Hopkins and Decatur, Illinois, Downes Syndrome children with intestinal atresia were denied surgery and food and permitted to die because the children were mongoloid even though the atresia problems involved are usually treatable and the prognosis good. In other words these children were really caused to die because (1) they were not given

the corrective surgery they needed, and (2) they were not given sustenance.

3. The legal ramifications of the above may be summarized as follows: Parents who withhold ordinary care from a defective infant, as well as physicians, nurses and hospital officials who acquiesce in the decision, risk liability for crimes ranging from homicide to neglect and violation of child abuse laws. In addition the physicians, hospital and involved hospital personnel risk civil liability through malpractice damage suits.

Although there is little case law on the subject of active euthanasia per se,

a) Criminal prosecutions for active euthanasia are still rare and convictions even more rare. Juries have been more than willing to find that a defendant on trial for a mercy killing was temporarily insane. There are a few cases that hold it is murder, People v. Conley, 49 Cal. Rpt. 815, 411 P. 2d 911 (1966); State v. Ehlen, 98 NJL 236 (1922); Turner v. State, 119 Tenn. 663, 108 SW 1139 (1908)

b) Civil liability for active euthanasia - a physician might be liable for an intentional tort for wrongful death, probably would not be covered by his malpractice insurance policy since intentional or criminal acts are not ordinarily covered.

c) Criminal Law - Omission to Act. There is no known criminal case against physician or hospital for a refusal to render treatment. Some lawyers, however, believe that criminal prosecution for failure to provide ordinary medical treatment may be a homocide. and the doctor and nurse could be prosecuted under certain situations, i.e., doctor agrees to treat and then refuses; or if special statutes require the taking

of protective action in the case of child neglect laws.

d) Civil Liability - Omission to Act.

A doctor is under no obligation to treat anyone; if he undertakes to do so, the law may impose liability upon him for failure to exercise ordinary care.

I am not aware of any case where a medical malpractice claim has ever been filed against a physician who, in a terminal situation, and with the consent of the family, ended the extraordinary means that were being employed to prolong the life of an already terminally ill patient who is in the death process.

If the physician is charged with active intervention to end life, criminal or civil liability may attach. However, there are no known tort cases arriving out of active euthanasia situations.

4. Consent. It appears legally and morally proper for a parent to give consent to termination of extraordinary means of prolonging life. It does not seem legally or morally feasible that a parent should be able to refuse consent for ordinary or even extraordinary medical means if the treatment may reasonably be expected to be beneficial to life. Thus in the Downes Syndrome cases mentioned earlier, a parent could not consent because that consent would begin the death process rather than constitute its natural termination. Thus parent, guardian, physician and hospital administrator could very well be subject to liability.

The Danger of Over-Reaction to the Horrors of Hitler

1. Prolongation of life may not always be in the best interests of the child, sometimes shortened life may be in the child's best interest. An over-reaction by our courts and our legislature and

our medical profession could result in either a useless, painful, costly, horrible living experience for a person whose best interests could be served by death rather than life.

2. Detrimental experimental surgery could constitute a guinea pig human submission to medical torture. (Give example)

3. The prevention of consent by a parent or guardian to the withdrawal of useless medical, surgical and hospital tests and procedures could smack in the face of sound medical and moral practice.

4. Emphasis upon criminal and civil liability for parents, and doctors, hospitals could result in so much bureaucratic red tape that parents and physicians would hesitate to attempt extraordinary and heroic efforts to save as opposed to kill children.

5. Frequently over-reaction to the horrors of Hitler have denied rights to the retarded. For example, federal funds have been denied to retarded persons desiring sterilization and abortion who could not afford to secure same. I fear too much rather than too little court and professional interference in these areas and believe that generally speaking the parent or guardian, the retarded child or adult, and the physician are better qualified to make decisions even though some mistakes will be made than to rely upon courts, legislatures, and hospital committees.

6. Although many people despair of the Karen Quinlan Case, and although I deplore some of the language used by the court in the decision (namely "the return to a cognitive sapient life"), I did agree with the court's holding:

> 1) That in certain circumstances an individual has the right to decline medical treatment even if death will result. The State's interest in preserving life weakens and the individual's right to privacy grows as the degree of bodily invasion increases and the prognosis dims.

2) that the guardian on her behalf would exercise this right.

3) the father could secure other doctors if those doctors concluded and the hospital ethics committee agreed that there was no reasonable possibility of Ms. Quinlan's returning to a cognitive sapient state and if the doctor recommended discontinuance of the life support apparatus, and it could be withdrawn without any civil or criminal liability therefor on the part of any participant.

7. There could also be a real danger to a retarded person if either he or his parent and guardian could not refuse medical treatment. The "normal" person has this choice; he can refuse medical advice and look elsewhere for other medical advice. The over-zealous professional could have a field day if the law prevented withdrawal of treatment and consent to treat the unnecessary.

8. There may well be a few, and I stress very few, retarded persons who not only should be permitted to die but possibly, and I say this guardedly, should be aided in death.

a) the person who has anencephalus or hydranencephalus

b) the person who to a reasonable medical certainty is irreversibly comatose

c) the person who to a reasonable medical certainty has horrible pain that cannot be controlled by medicine and which will last for his lifetime

d) the person who to a reasonable medical certainty will die within a relatively short time irrespective of the most advanced medical and surgical intervention

e) the person who to a reasonable medical certainty has such little brain function that he cannot enjoy food and drink, a touch or kiss of a friend or relative, music,

or any human relationship whatever and who is unable to utilize his limbs, control his bowels and must for his lifetime be on a respirator and tube fed in order to live. Is this life? Is this living torture or living death?

Conclusion:

1. A retarded person should never be caused to die by the withholding of ordinary or extraordinary medical treatment if such treatment can reasonably be expected to cure the condition which will produce death in the absence of same.

2. A retarded person should never be refused treatment because he is retarded if a non retarded person could reasonably be expected to receive same.

3. A retarded person should never be denied ordinary treatment or extraordinary treatment because he can't afford it or for quality of life reasons, or because his basic costs will have to be paid for by society.

4. A retarded person, who to a reasonable medical certainty, will die in the reasonably near future (even if extraordinary treatment is given) should have the right to die and should have the right to have his parents consent for him to refuse useless surgery and medical treatment and to withdraw respirator and other artificial means of keeping him alive.

5. A retarded person should have the right to an abortion or to sterilization as well as the right to decline either. These rights should be protected with a minimum of court, legislation and professional interference but he or she should have the benefit of professional unbiased counselling.

6. A retarded person should have the right to donate an organ for transplant if to a reasonable medical certainty the risks to his life and health are minimal.

7. There may be a very small number of retarded persons who have no, or so little, brain function and who have so many other severely debilitating physical defects where the right to die should be encouraged over the right to a prolonged living death.

8. Although we must fight hard against the Horrors of Hitler and Sackett and other professionals who would actively commit euthanasia upon large numbers of retarded prsons by medical management, we must also be very careful that in our desire to protect the rights of the retarded we do not destroy his right to life, liberty and the pursuit of happiness by imposing upon him too much protection, governmental interference, litigation, court, medical board and welfare board involvement.

9. We must also be careful that we do not have courts telling doctors how to practice medicine or encourage medical malpractice suits and suits against parents to the point that the doctors will be afraid to delve into the unknown to attempt to save life or that parents will have to go to court to make the most elementary normal decisions for their retarded sons and daughters.

10. We must hopefully continue to learn more about retarded persons, involve them more in the decision making process and see to it that neither parent or professional over protects or usurps those rights to make decisions which the retarded person can make for himself. On the other hand, civil rights without appropriate education and guidance and counselling can also prove chaotic for the retarded person.

11. The rights of parents and their normal offspring should not be confused with the rights of the newborn retarded child's right to life. However, neither should the parents right to life, liberty and the pursuit of happiness be overlooked by virtue of their having born a grossly defective child who may require 15 to 20 surgical procedures and long-term hospitalization and nursing care. The

parents decision to treat should be eased by providing catastrophic insurance benefits to protect against the $300,000 hospital bill, being forced into bankruptcy, or to accept medical assistance poverty eligibility requirements, or forced to give up all rights to the child. Unfortunately, the latter happens today--I have seen it.

Thank you, though I spouteth too much.

Melvin D. Heckt