May we take baby Theresa’s organs to save other children?

On March 21, 1992, baby Theresa Ann was born. Prenatal tests had determined that the developing fetus suffered from anencephaly. This is a condition in which infants are born with only a brain stem which controls basic functions such as breathing. The higher centers of the brain necessary for human consciousness are absent. Many such children are stillborn. When they are born living it is rare for these infants to survive for more than a few days after birth. Baby Theresa’s parents were aware of this situation. However, they decided to allow the pregnancy to go to term in hopes of donating their baby’s organs to other newborns in need of them. Infants with anencephaly are not brain dead because they have a functioning brain stem and so it is illegal to harvest their organs. Waiting until brain death usually results in such deterioration of the infant’s organs that they are no longer suitable for transplant. Theresa’s parents petitioned to have her declared brain dead so that they could donate her organs to other children. The court refused their request and Theresa died a short time later.

We can look at the issues involved here from the perspective of individual ethics, institutional ethics, and societal ethics.

Individual Ethics

Here we try to decide how to best serve the interests of the individual involved—baby Theresa, her parents, the potential recipients of her organs. A central concern is the good of baby Theresa. What protection and respect do we owe her? Many would argue that she must be treated as any other dying patient (as the present brain death laws insist). Taking her vital organs is killing a severely handicapped child. Others argue that she should be treated as if she were brain dead (as the German courts allow) because she lacks the very center of personhood—the neocortex.

Should the only basis for a decision be what the parents think is in their child’s best interest? Or are there other considerations—as there are in the case of Jehovah’s Witness parents deciding about a blood transfusion for their child?

Often considerations such as these on the individual level are sufficient to decide the case. But sometimes the issue involves such social change that the level of societal ethics is decisive.

Societal Ethics

Societal ethics looks beyond the single case and asks about longer time frames and broader circles of life. It looks carefully at the existing priorities and habits of society and asks about how this society might further evolve if we introduce these patterns of acting. In short, will society in general be better off ten years from now if we start acting this way?

Some argue that we will save many children who would have died otherwise and that this will demonstrate and deepen our commitment to saving children. Others note that we are already extremely neglectful of our most vulnerable citizens—our children. (By the year 2000 one in four children will live in poverty, and over half of our poor children do not qualify for Medicaid.) A fear is that using the organs of not-yet-dead children will further dull our concern for children by promoting an attitude that measures a child’s value by its usefulness to others rather than as a value in itself. If the organ transplant movement is seen as callous to our most vulnerable patients it will lose credibility with the general public.

A further concern comes from the experience at Loma Linda University’s Medical Center in California. They started but later discontinued a program in transplanting organs from anencephalic infants. They discovered that anencephaly is a blurred category—not only in the minds of people on the street but also in the minds of physicians and other health professionals. A surprising number of children were referred by health professionals as possible organ donors who were clearly not anencephalic.

Many suffered from a less severe deficit.

For these and other social reasons many argue that we would do an extreme disservice to our society by allowing the harvesting of organs from not-yet-dead children with anencephaly.

Institutional Ethics

Each institution will have to arrive at some clarity about the issues sketched above. Then they can decide what their position will be concerning such practice. Should they remain silent and leave this issue to the politicians, the churches, and educational institutions? Should they take up the role of social change agent—advocating for change in current law and practice? Or should they push to keep the restrictions that now exist? What educational efforts should they make—inside their own institution and/or in the wider community? Even inaction represents a decision.

An essential first step in dealing with ethical issues is to determine on which level we are working. Then we can decide who and what ethical tools are needed to address adequately the question on that level. The people and tools suited to one level are not always appropriate for other levels.