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27. NON-TREATMENT OF SPINA BIFIDA BABIES

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ABSTRACT. This article presents a philosophical framework for physician-family ethical decision-making for the controversial cases of withdrawal, initiation, or continuation of treatment for *spina bifida* infants. The well-known criteria for selective treatment proposed by Lorber are shown to be ethically sub-optimal on the grounds that they are based on a general conception of the decision framework that is open to serious criticisms and questioning.

We propose a model of joint physician-family decision-making that we think represents a more rational method of balancing patient autonomy with the professional expertise and international moral norms of physicians. We raise serious reservations about the wisdom of allowing the state to intervene too strenously in this type of decision, in many cases.

To be, or not to be, that is the question,
Whether tis nobler in the mind to suffer
The slings and arrows of outrageous fortune,
Or to take arms against a sea of troubles,
And by opposing end them. . . . (Hamlet)

Spina bifida is a birth defect that has occasioned several controversies in recent bioethical literature. First, the attention of the public has now been drawn to cases where failure to treat resulted in the deaths of *spina bifida* babies. Can this condition be so hopeless that it is kinder to withhold treatment and allow such a child to die mercifully? Some commentators have argued that if so, it should be even more humane to allow active killing of these children.[1] Medical selective diagnostic criteria for making the decision to treat or not have raised other questions. Should the decision be thought of as a medical one, to be made on the basis of medical criteria by the doctor, or is it a moral decision with the main burden being on the parents to decide? Some of the ethical disputes that have taken place suggest that there is confusion or unclarity about how serious *spina bifida* really is as a disability.

We survey recent developments in ethical controversies on whether some form of selective treatment is appropriate for children with *spina bifida*. Beginning with a basic description of the physiology of

this disability, we go on to discuss how serious it is, to review proposals for selective treatment, and examine some case studies of family welfare. We suggest that proposing precisely formulated selection criteria for the decision processes is not, at any rate by itself, the best approach. We think the decision-making process should ideally be a reasonable two-way dialogue between the baby's representative (normally the family) and the physician (including other relevant medical staff). Utilizing selection criteria that purport to be purely medical--especially if they are not--can tend to usurp patient autonomy or input through the patient's family that should properly play a role in the decision process.

1. WHAT IS *SPINA BIFIDA*?

Dysraphia is incomplete closure of the neural tube, the embryonic central nervous system that develops into the brain, spinal cord, and spinal column. When the tube remains open at the top and the baby is born with cerebral hemispheres either entirely missing or reduced to small masses at the base of the skull, the condition is called *anencephaly*. When the defective closure is further down the tube,the anomaly is called *spina bifida*. If the spinal cord or the meninges, the membranes surrounding the cord, protrude through the bony encasement, the defect is called *spina bifida cystica* (open *spina bifida*). Otherwise, the condition is called *spina bifida occulta* (closed *spina bifida*). The open variety is sometimes also called *spina bifida manifesta* or *spina bifida aperta*. The seriousness of the condition depends on both the position of the lesion and the degree of displacement of the spinal cord. Lesions nearer the head tend to be more serious.[2] Many people have *spina bifida occulta* without being incapacitated at all. The disabilities consequent upon *spina bifida cystica* are in many cases very severe.

Some other terms are often used in discussion of *spina bifida*. *Meningocele* refers to protrusion of the spinal membranes through the bony encasement of the cord, forming a sac filled with cerebrospinal fluid and covered with skin. This fluid is formed within the brain, and passes out from ventricles in the roof of the hindbrain, to be absorbed into the bloodstream. When the hindbrain is malformed, as in some cases of *spina bifida*, cerebrospinal fluid cannot escape. The resulting accumulation of fluid causes the skull to enlarge, and a *hydrocephalus* is formed. This condition is accompanied by stretching and thinning of the cranium and separation of the cranial bones. When the spinal cord as well as the spinal membranes protrude through the bony fissure into the sac, the condition is called *meningomyelocele*.

The malformation whereby the hindbrain is distended and protrudes down into the spinal canal is called the *Arnold-Chiari Syndrome*. When there is a hydrocephalus, the generic method of treatment is to insert a shunt linking a brain ventricle with a vein returning blood to the heart so that the excess fluid is harmlessly drained off into the bloodstream. The use of this method, in conjunction with sewing up the damaged region of the spinal cord, has greatly increased the chances of survival for many *spina bifida* babies.

Many other disorders are associated with *spina bifida*. Deformities of the spine or legs may require orthopedic surgery. Poor bladder function often results in kidney damage, infection, and sometimes a need to

divert the ureters through the abdominal wall for urine excretion. These treatments are not a cure for the underlying condition, which began before birth and may have resulted in damage to the nervous tissues of the spine. It is not known what causes *spina bifida*. For all anyone knows, it seems likely to be a combination of genetic and environmental factors. At present there is no known cure.

2. HOW SERIOUS IS *SPINA BIFIDA*?

Spina Bifida, in general, occurs in one to three per one thousand births, and *spina bifida occulta* is the most common form. It is an isolated, insignificant finding involving about twenty percent of all spines examined. A small percentage of these infants have functionally significant developmental defects. Most affected infants have no symptoms and no externally visible sac, although, when there is involvement, neurological impairment may gradually worsen, especially during adolescent growth. In this case, surgical repair of the internal opening or spinal column defect can be undertaken if it can be done without damage to neural structures.

The meningocele form involves an external, cystic defect which usually leaves the spinal cord and nerve roots normal, although surgical correction is necessary to prevent sac rupture and subsequent infection. After surgery the prognosis is good. But about nine percent of these infants have associated hydrocephalus which may be aggravated after surgery. Meningocele is not usually associated with the Arnold-Chiari malformation, that is, defect of the brain stem and cerebellum.

Meningomyelocele is a more serious condition. Almost all cases are associated with the Arnold-Chiari syndrome. Because of this, approximately ninety percent of these children develop hydrocephalus. The prognosis depends on the extent of the motor deficit, involvement of bladder innervation and associated cerebral anomalies at birth. Total paralysis of the legs and urinary bladder present a poor prognosis even with optimal medical care; the majority die in early childhood from complications of hydrocephalus therapy and chronic renal failure. All survivors are restricted by motor disability and fifty percent are mentally retarded.

In short, the possibility of a successful life for those infants with *spina bifida occulta* and meningocele, without neurological deficit at birth, is good. But in severely affected infants--those with meningomyelocele--ninety percent will die within one year without surgical intervention. Generally, prognosis is poor for those infants with associated hydrocephalus.[3] This variability of prognoses helps to explain some recent controversies about the seriousness of *spina bifida*. According to Kolata (1980, 1218), recent statistics given by physicians concerning survival rates and extent of disabilities have tended to be pessimistic, whereas the Spina Bifida Association of America has stated that normal intelligence, lifespan, and contribution to society can be expected for *spina bifida* children. It seems that a more realistic picture lies somewhere in between. LeRoy Walters of the Kennedy Center for Bioethics states that 33 to 63 percent of *spina bifida* children have I.Q.'s above 80, but if there is no hydrocephalus, 83 to 90 percent have I.Q.'s above 80. But according to Walters, twice as many *spina bifida* children have hydrocephaly as do not.[4]

3. SELECTIVE TREATMENT

It becomes apparent from the above information that there is a great degree of variability within *spina bifida* and that a majority of affected children are "savable". But what of those children who are probably savable but considered unlikely to have a "successful" form of life?

In recent years, with the advent of new surgical procedures for neural tube disorders, serious ethical problems have arisen with proposals for "selective treatment" of these children. Many questions have emerged regarding the misuse of medical technology for saving "useless" lives, thus inflicting tremendous emotional and financial stress on families and society and causing the survivors to suffer unnecessarily.

As J. Lorber was a pioneer in the study of selective treatment for *spina bifida* babies, it might be best to look first at the clinical study from which his theory was derived. Lorber (1975, 47) argues:

> The indiscriminate use of advanced techniques of all types has kept alive those who would have died but now live with distressing physical or mental handicaps or both, often for many years, without hope of ever having an independent existence with compatible dignity.

Lorber came to this conclusion from treating infants with meningomyelocele, from the first day of life, from which it was expected the best results would be achieved. From 1959 to 1968 he and his colleagues treated 848 infants aggressively, with 424 survivors, 345 of whom he described as severely handicapped. Fifty-one percent of the 848 were deemed retarded as well. He estimated that five percent of the original 848 would be employable. He estimated that the cost of medical care and special education would exceed #50,000 by age 16 for each severe case. Moreover, he noted that many of the mothers were on tranquilizers, that siblings suffered, that families broke up, and that many which remained together did not attempt to have further children.

With these data in mind, Lorber set out to establish criteria so that no infant with a chance of survival would go untreated. He implies a cautious approach, claiming that the forecast of minimal handicaps was easily done on the first day of life and, thus, would still result in some severely handicapped survivors because deterioration could still occur after treatment.

Using Lorber's study as a baseline, we next briefly survey some of the rash of arguments and studies that it provoked. Lorber's opinion against the indiscriminate use of medical technology to keep alive those who do not have a hope for "independent existence with compatible dignity" in itself raises a considerable question, since this strongly appears to be as much a moral as a medical notion. Different people would presumably have pluralistic conceptions of it. A Working Party Report (1975) pointed out that "those who seek to judge happiness judge it ac-

cording to their own standards", and observed that congenitally blind children adjust to school much quicker than those who had sight and lost it.

Lorber remarks that the lingering death suffered by some of these babies is almost enough to suggest that for some *spina bifida* babies, active euthanasia would be the most humane way to deal with the situation.[5] However, he argues that giving anyone the legal power to kill would be too dangerous, and that therefore he cannot sanction active euthanasia. On the other hand, Lorber (1975, 58) argues that not treating is not necessarily equivalent to passive euthanasia--non-treatment is different from purposeful death. The active-passive distinction is currently very controversial among moral philosophers--for an analysis of it, see Walton (1979). However, even granting Lorber's use of this distinction, the question should be raised of what he means by the terms "independent existence" and "dignity".

Lorber himself however does not openly stress quality of life factors, only rejecting (1975, 58) the idea that life must be maintained at all costs. Surely, however, the question of the quality of life for these children cannot but be a major factor for anyone who argues that these children should not be treated on the grounds that they cannot hope for an independent or dignified life. It is important to see the basis of Lorber's selection criteria is not purely medical or statistical in nature-it is partly moral, a question of personal values.

S.A. DeLange (1974) feels that medical consideration alone for selective treatment cannot be justified because, "the problem of involuntary euthanasia is one that touches the very foundations on which our humanitarian civilization is built". He feels that once criteria are set, no matter how low the minimum specifications, it would be illogical not to apply them to other categories of handicaps. Although passive euthanasia cannot be condemned in all cases, the ethics behind these decisions must be carefully analyzed. In the case of deformed children, there are actually two sets of ethics involved: those involving the patient and those involving the family and society.

Regarding the family and society, Lorber and others have raised the issue of the cost of treatment of these children. E.M. Cooperman (1977) argues:

> We cannot continue to direct large sums of money to the care of hopelessly handicapped children while many others around the world have no food or clothing; we cannot agree to full treatment for hopelessly handicapped children when old people in perfect physical health within the same community live and die in poverty. (1340).

While this sort of statement may seem, at first glance, to have some degree of validity, it may actually be evading the issue, at best, and, at worst, may be making a statement that all worthwhile people are disease-free. The idea might even eventually be extended to the old, helpless people Cooperman proposes to support. As Sherlock (1980) points out, selective criteria based on the judgment that a life is "not worth living" are vague. Hence it is not clear whether they can be consistently applied to other relevantly similar cases, e.g., adults with severe disabilities, or other children with somewhat less severe disabilities. If

such procedures cannot be consistently applied, and may therefore vary with the emotional preferences of parents, they cannot be fair to the infants.

4. FOLLOW-UP STUDIES OF SURVIVORS AND FAMILIES

Another point of considerable debate concerns the emotional stress a disabled child causes parents and families. According to Lorber, the family situation quite often suffers unnecessarily. There is an abundance of literature on this topic which gives a great deal of insight into the actual results of such a situation.

It may be as DeLange (1974, 28) indicates, that the medical profession tends to strongly influence any negative feelings acquired by parents upon the birth of a disabled child as, "it very rarely happens after extensive talks that parents persist in an opinion different from their doctors", This could quite often be the case although it is interesting to note that according to Brunner and Suddarth (1974, 1329), nurses are instructed to "emphasize what is *normal* and *well* about their 'the parents'§ infant". Nevertheless, while this may apply to the nursing profession, the trend toward selective treatment causes decisions to be made by the medical profession. A case of such a decision is cited by Reich (1973). The parents were informed of their newborn infant's condition and advised that it would eventually die, probably to the benefit of all concerned, without treatment. The parents, so-influenced, agreed. In the meantime, the couple returned to the hospital daily, became fond of the child and reversed their decision for nontreatment when the baby contracted meningitis. The child was reported as doing well at age six months, although it was too soon for mental assessment, and the parents were reported as adjusting well. It was also noted that the family was financially stable with a good medical insurance plan, so that costs could not have influenced the decision.

DeLange points out that the time for decision-making is a very emotional period for the people involved, the physician included. This may further complicate an already grey issue.

R.B. Darling (1977) conducted a study to investigate the problems and adjustments of *spina bifida* children at home. She chose twenty-five children ranging in age from three weeks to nineteen years. She discovered that all parents interviewed had positive attitudes, and that the most important influence on their attitudes was interaction with the child itself. Many felt that once their child was born, its life was valuable. Darling's findings indicate that a life defined by the physician as intolerable might be defined very differently by parents and suggest that physicians should not deprive parents of a child that they will grow to want.

Farber and his associates--See Robinson and Robinson (1976, 427-30)--also made some interesting observations in their study of mentally retarded children in the home. They found that the presence of retarded children does indeed tend to place additional stress on the family and that the child may even serve as a "scapegoat" for problems that antedated its birth. It was also noted that the siblings were affected primarily as conditioned by the parent's attitudes. However, the significant point is made in their conclusion that the retarded child is far less

a threat to family unity than are such things as chronic illness, imprisonment or death of a family member, or for that matter, economic defeat through job loss or business collapse. Farber concluded the study noting that, "most families are able to adapt positively and effectively to this chronic situation". (Robinson and Robinson, 1976, 431).

While Darling and Farber paint relatively rosy pictures of the situation, a series of studies initiated by B.J. Tew (1973), (1974), (1977), shows a different set of statistics for the outcome of family relationships. In a statistical analysis of 146 families having a child with one of the major neural tube malformations, it was found that the severity of the handicaps influenced the quality of the marital relationships. Also, the divorce rate among *spina bifida* parents was almost twice that of the national average. Tew notes that in a marriage where prenuptial conception has taken place, the usual event is "cementing" of the union upon the birth of a normal child, whereas an abnormal child may weaken an already weak marriage. The birth of a second, normal child, on the other hand, causes a positive effect and makes the couple better able to cope with the handicapped child. A significant point is made in showing that because *spina bifida* is evident from the moment of birth, it has a more severe impact than other handicaps that manifest themselves later in life. This provides another argument against decisions made at the time of birth. Most parents with children afflicted with a similar disease, that does not become apparent until later in life, would want every conceivable treatment made available. Many *spina bifida* afflicted children do not benefit from this, which Darling refers to as "growing to want".

Tew also used an objective method in assessing maladjustment in siblings of *spina bifida* children. Although the frequency of maladjustment was found to be four times higher in siblings of *spina bifida* children than siblings of normal, control children, it is noteworthy that no difference was observed in the scores of the first group when the *spina bifida* children were at a residential school compared to those at home.

It seems apparent when reviewing these studies that, indeed, there is disharmony as a result of the birth of a child with *spina bifida*. But on closer scrutiny, disharmony may not be caused so much by the actual prospect of hardship as much as by the stigma attached to its birth and perpetuated by the expectations of society, including the medical profession. DeLange (1974, 28) feels that, "it would be deeply contrary to our prime objective °to serve the patient to the best of our ability§ in allowing a child to die because of inconvenience or unhappiness to the family". He suggests that the child be institutionalized instead.

P.M. Black (1979, 336) notes the significant point that some studies should be done on the results of parents' psychological status after the decision not to treat. Comparisons should be made between those families with a handicapped child, and not with families that never had such a child. It may be found out that, in the aftermath, the guilt and regrets outweigh the burden of supporting the child.

Because selective treatment is new in terms of the history of *spina bifida*, there are a number of case studies available on those people who have survived from the period before selection began. From Lorber's study, when he treated all cases, half died regardless. Therefore, these studies are the results of full treatment of all individuals.

A series of interviews was conducted by McAndrews (1979) of surviving meningomyelocele patients born at the Royal Children's Hospital in Melbourne, Australia, between 1950 and 1960. These thirty-five people were graded according to Lorber's classification, that is, from "no handicap" to "severe handicap". The results indicated that most were independent in their personal care and had devised methods for coping with household chores. They suffered the same problems with architectural barriers as do other people in wheelchairs and on crutches. Almost half had received their education in ordinary schools with one later transferred to a school for the physically handicapped. These children indicated that they had had social problems with other children teasing and staring, and surprisingly, with teachers who did not understand their disability. The rest of the group had gone to schools for the physically disabled but eight were later transferred to ordinary schools. Seven of the group had undertaken post-secondary training courses, two of which were full-time university students. Of another eighteen who had completed their schooling, three were in open employment, seven in sheltered employment, because of some degree of intellectual impairment, and eight were unemployed, two of these because of physical disabilities such as poor bladder control, high blood pressure and kidney failure. Nine attended a governmental rehabilitation center. It is also interesting that of the nine children who had attended both ordinary schools and special schools, all preferred the ordinary schools because of poor academic standards, separation from the community and over-sheltering experienced in the special schools. McAndrews (1979) concludes:

> The young person's ability to cope with physical and emotional situations is ultimately not determined by the severity of the disability but is a product of environmental support systems that have been available to him since birth. (628)

This particular study is of special significance because these young people were all born with meningomyelocele; not *spina bifida occulta* or meningocele. The results do not exactly coincide with those Lorber predicted and indicate the majority are "just people" with problems. While their status at birth is not mentioned, one wonders how many would have been selected out and "saved from distress" under Lorber's medical guidelines.

Dorner (1975) conducted a similar study to that of McAndrews. In forty-six cases, eight were excluded because of low I.Q.'s, two refused to be seen and a further seven could not be seen alone. Of the remaining twenty-nine, fifteen had mild handicaps, seventeen moderate and fourteen severe. Of the total forty-five, twenty-three were out of school, eight of whom were in open employment and seven in post-secondary education. Six were not working, the reasons for unemployment varied from limited intellectual ability to particular physical impairments.

Both of these studies statistically indicate that the outcome for *spina bifida* afflicted children may not be quite so bleak as might be felt when first encountering Lorber's analysis. A distinction is made in these studies in that a good number of these children do not suffer severe intellectual loss. Considering that Lorber treated 848 of these patients in almost a ten-year period, this would constitute approximately eight-five children per year. When it is further considered that half of these children could not be saved by technological means, we are now

referring to approximately forty-five per year. From the evidence presented by McAndrews and Dorner, many of these suffer only physical impairment, however severe. The actual number of savable children with severe intellectual impairment seems to be relatively small, even when considering Lorber's estimate of fifty percent. Even considering intellectual impairment, there would be a great deal of variability of severity within this.

This raises the problem of the precariousness involved in setting criteria for the selection of such children. How can a line be drawn? Should severe physical handicap be acceptable or should mental retardation be the cut off, and, if so, what level of intelligence is acceptable? Even if this sort of agreement could be accomplished, just how reliable are the criteria so that no acceptable child dies? A number of studies cited by Laurence *et al.* (1976) reveal that while physical disability may be quite accurately predicted at birth, future intelligence may not be. In fact, withholding treatment may actually worsen the situation of those who survive despite nontreatment selection--see Black (1979, 337).

The problem with Lorber's criteria is that they include not only those children with physical and mental handicaps, but also those with physical handicaps only. This is a questionable practice when one considers that a person physically disabled later in life is not "selected out". Of course, this point applies to people who suffer forms of brain damage as well. It is also noted that the criteria are not foolproof-prediction of outcome can be wrong. Reid (1977, 17) cites a case of a child who was still alive at eight years of age; blind, incontinent, with dislocated hips and an I.Q. of 80. His parents had been told, confidentially, that he would die soon after birth.

A basic problem inherent in selection criteria is that by incorporating subjective notions concerning the quality of life of those affected by the decision, they go too far in the direction of attempting to make a largely moral and personal decision by appeal to ostensibly physicomedical parameters. We agree with Black (1979) that more work is needed to try to sort out between factual questions verifiable by appeal to empirical data, and moral questions that are not even in principle empirically testable.

5. PRENATAL DIAGNOSIS

It has been suggested that prenatal diagnosis and subsequent abortion of these fetuses may be a preferable approach. The problems with this are much the same as those of selective treatment, especially the reliability of outcome. Hardly anyone well informed would argue against the termination of fetuses with anencephaly or very large encephaloceles as there is nothing gained in trying to treat these cases, and the mother is made to suffer physical and emotional stress.

The problem arises once again in where to draw the line, and is further complicated with the notoriously controversial question of when life begins. For those individuals who equate a fetus with a newborn baby, there is the problem of harsh guidelines applied before birth having to apply postnatally as well.

While the questions of when life begins and the ethics of abortion in themselves would require another paper, comparisons of the ethics of selective abortion with selective, passive euthanasia have been made, and should be mentioned. John Fletcher (1975) presents differences between the two which makes abortion seem the lesser of two evils. He points out that a newborn infant is apart from its mother and is clearly an individual patient. Before birth, the well-being of the fetus cannot be considered apart from the mother's condition. The responsibility after birth lies in the growing claims a new human life can place upon society. He also notes that, from a practical standpoint, a newborn infant is available for palliation or even cure, whereas, a fetus is not. With intrauterine fetal surgery being done, this statement is no longer true. For those who don't believe in abortion anyway, this relocation of the problem does not improve the decision. Moreover, not every *spina bifida* baby is, at present, diagnosed prenatally.

Ethical issues associated with prenatal diagnostic procedures for dysraphic defects are outlined by Kolata (1980). Screening test kits have now been developed that can detect an abnormal amount of alpha-fetoprotein in the blood of a pregnant woman. A fetus affected by a neural tube defect increases the amount of this protein in the maternal circulation to the extent that an abnormal amount of it is a good indicator of an affected fetus. If the result is positive, an ultrasound scan can give an indication of the nature and extent of the dysraphic defect. How widely these tests should be made available is a subject of current controversy. One particular question we return to below concerns the nature of the counselling that takes place when a dysraphic prenatal finding is diagnosed.

6. THE DECISION-MAKING PROCESS

Who should make the decision to treat or not to treat? We think that the parents must in the end usually be the primary decision-makers. Since they normally represent the baby, they bear the burden of representing the baby's right to refuse treatment, or to ask for treatment. However, the parents must make this decision only in consultation with their physicians. And a physician has the right, indeed sometimes the obligation, to challenge the parents' decision if he or she has reason to believe it is not based on the baby's best interests. Traditionally this has meant that the physicians would challenge parents' dicisions not to treat a child, in some cases.

It would be easy to hypothesize that the decision should be structured as follows: the parents have to decide based on their moral values, and the doctors provide the input of medical facts. However, we think it is not so simple. For one thing, we have seen that ostensibly "factual" selection criteria contain considerable moral aspects. Moreover, the physician rightly has played the role of a moral counselor, to a certain degree, if his patients request it. While Black (1979) rightly advises that more effort is needed to sort out facts and values in the issue on *spina bifida*, it is not easy to simply bifurcate the whole process into medical facts--the province of the physician--versus ethical values--the province of the autonomous patient. Some of the pitfalls inherent in attempting to effect such a simple dichotomy are outlined by Sadegh-Zadeh (1981), who points out that value-ladenness of concepts is tied to a

number of variable parameters. The facts and values are tightly bound up in the practice of the decision process.

We think that the decision-making process is best thought of as a reasonable dialogue between the patient (or his representative) and the physician (including other relevant medical staff). In this dialogue, the physician presents facts, to be sure, but the patient has the obligation to study and understand these facts as clearly as time and ability permit. The informed patient must make a decision, to be sure, but must also take into account the wishes of the doctor, who, on medical grounds may (and perhaps should) press for one particular decision outcome. In the case of *spina bifida* counselling, a significant question is just how the physician puts the decision to the patient. How are the alternatives presented by the physician?

Lorber (1975, 54) states that it should be the doctor's duty to decide. He claims that the parents are hardly ever sufficiently informed, and they are also under severe emotional strain. He adds that there may also be an element of parental guilt if things turn out badly. Lorber concludes (1975, 54): "Of course, the parents' wishes must be taken into account, though usually they will ask the doctor's advice, even if the doctor appears to leave the decision to them". We think that Lorber has gone too far in the direction of proposing that the physician usurp the primary responsibility for the decision.

We think that the point about parental guilt is quite valid, and that the physician must sometimes present the decision as a medical one in order to help the family cope with the tremendous burden of guilt. But in general, we think it should be just the other way around from Lorber's way of putting it. The doctor may sometimes appear to make the decision herself, but in reality it is the parents who must really make the decision in the end, even if it is to agree with the doctor's preferences. The family, not the doctor, is normally the representative of the baby. It is the baby's fate that is primarily at issue. In the end, the physician does not have the right to make the final decision for the baby.

Lorber (1975, 54) states that in his experience no parent has ever wished for an operation after a full explanation of the baby's condition concluded with the advice by the doctor not to treat. This seems to us like a circular, self-fulfilling prophecy. Small wonder the parents agree if the situation is explained to them as decidable on wholly medical criteria. Thus despite our respect for Lorber's valuable contributions to this field, we feel that his approach tends too much in a direction away from patient autonomy.

However, the situation is a delicate one, and there is no known formula for sorting facts from values. Moreover, Lorber is quite justified in remarking that many patients--though not all we hasten to add--will not find it easy to grasp the situation, and will want the doctor to decide, no matter how the issue is explained to them. Moreover, we do not wish to deny that some kind of selection criteria could in principle be useful in facilitating the decision process. We feel that such criteria need to be evaluated however, to see to what extent they are factual (empirically testable) versus ethical propositions. Second, on the basis of our earlier findings, we do not feel that selection criteria should be parlayed as purely medical or factual propositions, if they are not, for

such a confusion usurps rather than facilitates the free dialogue of the decision process.

We feel that the decision-making process should be two-sided, in effect like a bargaining procedure. Both parties should air their preferences and arguments. Severe disagreements, especially if there is suspicion of special interests or unethical demands on either side, may at some point go to adversary legal procedures. Barring such exceptional cases, however, the process of decision-making should be a constructive one, based on mutual trust and truly informed consent on both sides. Naturally, the parents' wishes have a certain priority, as they normally reflect the interests of the baby, but that does not mean that the physician can relinquish her role as a moral counselor any more than as technical consultant. To deal with the problem of parental guilt, the physician must in many cases play a leading role in putting forth medical grounds for a decision to treat or not. At best, it must be truly a two-way dialogue. This method of dialogue as a procedure of decision-making is applied to the ethical problems of the intensive care unit in Walton (1983). As a general method, it has certain characteristics to be noted here.

The framework for decision-making usually given in ethics is that of maximization--the decision-maker looks over a finite set of given outcomes and picks the outcome where the product of probability and value of that outcome is the maximum over the given set. However, in the context of decision-making in doctor-family interactions in pediatric cases, it is hopelessly optimistic to think that such long-term outcomes in an individual case can be defined as nicely quantified outcomes. The model of maximization, while highly appropriate in some cases of proposed surgery--where outcomes can be assigned numbers on the basis of past records--can not usefully be applied in such pediatric cases as *spina bifida* decision-making. Not only are the probabilities of the outcome-alternatives disputable, but the idea of placing a definite value on any given postulated outcome approaches the absurd. Too much depends on how the disabled infant may impact on the family relationships, and other essentially non-quantifiable factors of this sort.

In this sort of situation, it is more realistic to opt for a less fine-grained procedure of decision-making called *satisficing* or *practical reasoning*, where the participants agree on certain common goals and then proceed by dialogue to agree on the best means, in the circumstances, to carry out these goals.[6] Instead of looking for the best possible solution--which may not be definable in any event--this decision-making procedure adopts a certain standard or goal, and then looks around for a reasonable way to realize that goal. This search-and-try process of decision-making is sometimes characteristic of patient-doctor interactions in some cases. For example, if a patient has a troublesome allergy, the doctor may try out different "reasonable" ways of attempting to contend with the problem, even if she realizes that none of them is likely to be the best possible "cure" for the problem. It may be a question of what the patient best tolerates within the constraints of particular goals and circumstances known to the doctor and patient.

Of course, in any doctor-patient interaction, the underlying goal should be the health of the patient. But there can be room for discussion on how 'health' is to precisely defined and reasonably implemented in a particular case. In *spina bifida* decision-making, the primary goal

should be the health or well-being of the baby. But the necessary means of carrying out or working towards this goal must impact on the family's well-being, and on the doctor's professional codes of ethics and personal standards. Hence it is best to conceive that the decision on how to best proceed towards the health of the baby, as well as that can be defined and understood in the particular circumstances of the case at issue, should be made on the basis of reasonable dialogue between the rational and concerned parties--namely the doctor and the family.

7. PHYSICIAN-PATIENT DIALOGUE

Of course, the State may have a legitimate stake in this process of dialogue in certain cases. But it is a mistake to think that the State should propound general guidelines to determine treatment (or non-treatment) in all cases. For such government decision-making is based on general, bureaucratic standards which have no place in realistic and reasonable interpersonal dialogue between doctor and patient (or patient's proxy). Moreover, legal debate and argument, based as it is on an adversarial method of decision-making or on legislative policies that apply in a general way to whole classes of cases, is only applicable where there is a well-defined conflict that prohibits a more co-operative doctor-patient approach. The method of dialogue tolerates considerable opposition, but it is based on the co-operative assumption of common goals and an underlying good will and trust. This personal tie of the doctor-patient relationship does not carry over in the same dialogue-oriented way to an individual's relationship to government regulations or to courtroom disputes.

Some would say that the method of dialogue is too vague or uncertain. We don't think that it is any more vague than any way of making decisions. Moreover, we think that using methods of decision-making that sound precise may be hopelessly inappropriate when they are applied to situations where probabilities and values for specific outcomes cannot be defined, and where there is no point in trying to wrestle with defining them in some fixed way. Realizing general goals, that can be clearly stated, in particular circumstances that may be very well defined in a given case, may best be done by agreeing on other interim goals and necessary steps to carry out these goals, by a procedure of reasonable dialogue. Failure to engage in this process of thoughtful dialogue may simply make the problem worse.

The problem is to see if there is enough of a basis to see doctor-patient decision-making, in regard to ethical decisions, as being logically reasonable enough to merit being safeguarded against the imposition of external criteria. A good example of an attempt to abrogate the doctor-patient relationship by external criteria is the letter in the United States from the Department of Health and Human Services in 1982 to hospitals stating that it is unlawful to withhold treatment based on the fact that an infant is "handicapped". This was essentially an attempt to impose a general rule on a whole class of decision-making situations that had previously been decided, for the most part, on an individual case-by-case basis by means of dialogue between the physician (or health care staff) and the patient (or in this type of case, the family). The problem is to see whether the existing case-by-case decision-making process based on dialogue is reasonable enough to justifiably sustain itself as a valid method of dealing with ethical problem-cases against gen-

eral (blanket) criteria imposed--for example, by the government--outside the individual physician-patient dialogue.

Stopping treatment is an awesome decision, not least in the following respect. Whoever feels that they have been personally responsible for the decision may have powerful and long-lasting feelings of guilt. For the family member who is asked to make the decision to stop treatment where this decision may be followed by the imminent death of the patient, there may be the feeling of being responsible for his death, or the feeling of possibly not having done the best for this person. Similarly, the decision is known to be a difficult one for the physician who may feel uncomfortable with this kind of responsibility.

In practice, consequently, the decision is often arrived at by a process of dialogue and collaborative decision-making where neither party need feel fully responsible for the decision. When the time comes when the physician feels that treatment is no longer required or beneficial, he may approach the patient or the patient's representative, and, in the context of the discussion, put the decision on a medical basis. Although the physician sees the decision as being made by the family member, he puts the decision in such a way that the family member can justify the decision on the medical grounds given by the physician. Thus the family member sees it as a decision made by the physician. But the physician sees it as a decision made by the family. Each can say that somebody else participated in the decision.

If you look at the physician's decision and the patient's decision independently of the process whereby they arrived at it, you might question the ethical basis of the decision, perhaps even think of it as a rationalization or questionable avoidance of responsibility. However, it is important to look at the whole context of the decision-making process. Let's say the patient is getting worse and worse. The physician comes to a realization that treatment is no longer doing any good, and that soon it will come to the point where to prolong treatment would be unjustifiable. However, he cannot make the decision unilaterally to stop treatment without consulting the patient or family. That would be paternalism of a bad sort. Therefore, all along, let's say, there has been an ongoing process of dialogue with the patient and family. Let's postulate that the patient isincapable of communication, but the process of dialogue with the family continues.

In such cases, it is very helpful for both parties to make the decision to have a sounding-board, a person with whom they can engage in back-and-forth discussion of the problem as it develops. This process is characteristically extended over a protracted period of time. Through it, each participant gets to know more about his own position on the issue, and the position of the other participant in the dialogue. When the time comes for the decision to be made, a basis for its justification is to be found in a basis of dialogue that has taken place and continues. When this process is working well, the decision can be based on a reasonable interaction. Hence the decision is genuinely interpersonal in nature, and not exclusively the outcome of one party's decision. Both parties bear a partial responsibility for the decision.

A rationalization is an argument arrived at on the basis of wrong or irrelevant reasons. For example if one party to a jointly-arrived-at decision were to say, "He's completely responsible. I had no part in it",

that would be a kind of rationalization. But if each party can say, "Yes, I was consulted and I had my position listened to and accounted for, but considerations advanced by the other party were a strong determining factor in arriving at the outcome", there need be no wrong or irrelevant reason involved. The family member can feel that he fairly advocated the patients' cause, and thereby participated in the decision-making process, without feeling he is the sole responsible agent. The physician can feel that he acted responsibly on a professional and ethical basis, in part due to the family's input being a decisive factor in the way the decision went. At least in many significant cases, there need be no rationalization or questionable avoidance of responsibility inherent in this type of process of decision-making. What makes the process reasonable as a sound ethical basis for the decision is the element of dialogue--the fact that it is truly a collaborative process of arriving at a decision on the basis of good reasons.

ENDNOTES

[1] Freeman, John, "Is There a Right to Die--Quickly?", *Journal of Pediatrics*, 80, 1972, 904-5.

[2] An illustrated outline of the etiology and development of *spina bifida* is given in Dryden, Richard, *Before Birth*, London: Heinemann Educational Books, 1978, 121-30.

[3] Brunner, Lillian and Suddarth, Doris, *The Lippincott Manual of Nursing Practice*, Philadelphia: J.B. Lippincott Co., 1974, 1324-26.

[4] See Kolata (1980), 1217.

[5] See note 1 above.

[6] For an overview of practical reasoning as a method of physician-patient decision-making, see Walton (1985).

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