

Mathematical formula decides life and death

Should handicapped infants be "allowed to die" with the consent of parents and doctors? This is the second article in a series that probes questions about the 5,000 annual "Baby Doe" cases that deeply divide medical, legal and government authorities.

By Carlton Sherwood
THE WASHINGTON TIMES July 10, 1984

OKLAHOMA CITY — When Joey Wade was born five years ago, the chances he would ever live a normal life were slim to none — at least that's what a team of physicians at the Oklahoma Children's Memorial Hospital here told his parents.

Joey was born with spina bifida — an exposed spine — and even with vigorous treatment, Dennis and Denise Wade were advised their newborn son not only would be "paralyzed from the waist down" but "severely retarded" as well.

"There was no guesswork," Denise Wade said, recalling the early meetings with the physicians. "He had brain damage. They said,



'We've done this CAT scan and he definitely has brain damage.' They also did this little pin test all the way down his legs and said he was paralyzed. We were told not to expect a whole lot out of him."

Despite the initial negative prognosis, the medical team, headed up by pediatrics chief Dr. Richard Gross, recommended Joey be placed on an aggressive treatment plan.

Today, after several operations and numerous visits to the hospital for therapy and checkups, Joey

experiences only partial paralysis in his lower legs and no apparent mental retardation.

With a success story like that, it would be natural for the Wades to have the highest regard for the physicians who treated their son — and, until recently, they did.

"The doctors were always so supportive and seemed to think the kids would be able to do more than most people expected," Mrs. Wade said.

see DOCTORS, page 10A

Doctors admit ethical problems

From page 1A July 10, 1984

Now, however, the Wades and a small but growing number of other parents whose children were treated for spina bifida at Oklahoma Children's Hospital no longer hold the doctors in such esteem. In fact, they admit to feelings of "bitterness" and "fear."

What disturbs the Wades and others is an article, authored by Joey's physicians and published in the October edition of the medical journal *Pediatrics*, describing how between 1977 and 1982 nearly 50 percent of their spina bifida patients were targeted for non-treatment — and how all 24 infants in that group died.

But perhaps even more shocking to the parents of spina bifida children who received expert medical care from the Oklahoma doctors was the way certain infants were selected for non-treatment.

In their report, the five-member medical team, led by Dr. Gross, frankly admitted they relied on a variety of "quality of life" factors while deciding which infants they would recommend for treatment or be "allowed to die." Among those:

- The parents' "economic and intellectual resources."
- The degree of paralysis or the infant's potential to live outside a wheelchair.
- The child's "neurologic status" or level of suspected brain damage and mental retardation.
- The accessibility of an "appropriate medical facility" for the infant.
- And, the "commitment by a social agency to provide needed resources" for the child's education and rehabilitation "later in childhood."

Mathematical formula

To underscore the point, the physicians wrote that their "selection program was "influenced" by a mathematical equation $QL = NEx(H + S)$, where the "quality of life" is determined by multiplying the "patient's natural endowment both physical and intellectual" by the sum of the "contribution from home, family and society."

During the course of their five-year study, the medical team evaluated 69 newborns with spina bifida.

According to the report, 36 children who met the "selection" criteria were given "early vigorous" medical treatment. All these children lived, except one who was killed in an auto accident.

Parents of the remaining 33 infants who failed to meet the program standards were told they "were not obligated to have the baby treated."

Eight families rejected the doctors' recommendations and insisted on "vigorous" treatment. Six in that group, including an infant described by the doctors as "robust and thriving," survived. One other child selected for non-treatment moved out of state and was lost to study follow-up.

The remaining 24 infants were transferred to the Oklahoma Children's Shelter, a federally funded intermediate-care facility neither licensed nor equipped to handle seriously ill patients. While at the shelter, the doctors wrote, none of the infants received medication, sedatives or "treatment for infection or other acute illnesses."

The doctors reported that all of these "babies died [at] between one and 189 days" of age, probably from "respiratory tract difficulties ... combined with an acute infectious process."

The physicians concluded:

"The untreated survivor has not

been a significant problem in our experience. All 24 babies who have not been treated at all have died at an average of 37 days."

The medical team said in the article that the "fate of the untreated infant has been a primary source of discomfiture" among physicians because selection programs raise "ethical" questions and could place

"But that shouldn't even enter into it. The doctors are there to heal, not to make qualitative decisions about where someone might be in 10 years. They have the skill to operate. ... So operate. Treat the baby. That's all we parents ask. Give us the burden, and let people take care of their own lives."

— Mrs. Veronica Donnelly

the hospital, the parents and themselves in a "precarious legal situation."

But, they noted, "The conclusive justification for selection in spina bifida cases appears to be the documented suffering that is not only reduced but prevented, if one is persuaded that death is preferable to life under certain circumstances."

Quoting from another physician's published opinions, the doctors wrote:

"Life ... is not to be sustained in the face of extraordinary hardships: These hardships can include physical, geographical and financial considerations."

The doctors said they considered "quality of life" factors so "crucially important" that children with identical birth defects could be treated differently, receiving "vigorous treatment" or "allowed to die" with no medical care at all, "depending on the contribution from home and society."

No regrets

Dr. Gross, the lead author of the article and the only member of the medical team who agreed to be interviewed, defended the selection process and the publication of the article.

"We described the process that I think is a good one," he said. "We found that virtually all of the babies that were treated survived and virtually all of the ones who had no treatment died."

Dr. Gross, now on the staff of Boston's Children's Hospital, said he firmly believes that there "has to be a way to finance this care" and, if that means measuring a child's quality of life against costs, "yes, we do consider some of those factors."

"It's not something that we as physicians should take into account — the ability to pay," he said. "On the other hand, every family has a finite amount of resources, and you have to distribute those resources in a certain way. If you have a family limited financially, emotionally and sometimes geographically, you're going to have to make compromises."

Dr. Gross acknowledged that at least 10 of the 24 children who died as a result of the selection process "would have survived" had they been treated, but he said, "family" considerations prompted a recommendation for non-treatment.

Asked if he thought the families would have opted for non-treatment without the doctors' recommending that course of action, Dr. Gross responded:

"If we had told them that they had to have their child treated and that he needed an immediate operation, I don't think they would have argued with us."

"It takes a great deal of courage on the part of parents to say in the face of a recommendation from a physician that they wish to go counter to that. They certainly do not have the background at the time

were circulated in Oklahoma earlier this year.

"When I read that, they're not the same people that I knew. The people who would do this would have to be cold, insensitive," Mrs. Wade said.

"I hate to think what would have happened if Joey had been in a little bit worse shape. At the time, we didn't know anything about spina bifida, and, if they told us there was no sense in doing anything for him, we probably would have accepted that. It's scary."

The same questions haunt Dennis Wade.

"I'd been up a day or two when I was at the hospital. I don't remember much about what went on, but I do remember the doctors told us that Joey would probably be retarded — severely retarded. As tired and confused as we were, we would have done anything they suggested. I guess we're lucky."

The Wades and other parents of spina bifida children say they have learned from experience that there is no accurate way to determine at birth how a child will develop mentally or physically.

"Look what they said about Joey when he was born," Mrs. Wade said. "Nobody would really be able to judge that at such an early stage."

Other parents, like Fred and Veronica Donnelly, whose daughter Catherine was also treated by the Oklahoma medical team, say it is impossible for doctors to determine how a family will cope with the problems of raising a handicapped child.

"No committee of doctors could predict how I would adjust to that because I didn't know and Fred didn't know how he was going to adjust to it," Mrs. Donnelly said.

"But that shouldn't even enter into it. The doctors are there to heal,



"If you have a family limited financially, emotionally and sometimes geographically, you're going to have to make compromises."

— Dr. Richard Gross

the child is born to really know what is expected."

Scary decision

Remarks like those hit close to home for the Wades and other parents of children with spina bifida.

not to make qualitative decisions about where someone might be in 10 years. They have the skill to operate. . . . So operate. Treat the baby. That's all we parents ask. Give us the burden, and let people take care of the complications.