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Counseling Parents of Defective Newborns

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COUNSELING PARENTS OF DEFECTIVE NEWBORNS

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AUTHOR'S PREFACE

I walk into the neonatal intensive care unit. It is a shiny, bright room of plastic, glass and metal. Everything is lined up in rows on either side of the room. My eyes immediately but tentatively take in the contents of the glass boxes --human babies. There is one baby that I could hold in one hand, with translucent skin, whose tiny lungs are being filled by a machine. Another baby, three pounds perhaps, with tubes in his nostrils and in his head. A plastic bag is stuck with adhesive to his almost microscopic penis. I become aware of the sound; rhythmic sounds of respirators as they breathe air into lungs which can't expand on their own; the gurgle of a machine which is bubbling air through water; a buzzer sounds. One machine is making a graphy on paper automatically pushing its way through; lights blink and wink on and off. I am aware only that there are many people present, nurses and doctors, some huddled over an isolette getting an IV started; there is, what seems to be, a lot of blood on the sheet. I swallow and straighten up a bit; I am aware that I am barely breathing. I want to scream. The atmosphere is one of professionalism. The people are anticipatory, watching ,waiting and doing their jobs efficiently. My knees begin to weaken. I leave.

I walk to the office and sit down. I am shaking imperceptibly. I feel as if each individual cell in my body is in shock. This is not the way a nursery is supposed to be. A nursery should be a happy place with fat little babies invitingly waiting to be hugged and cuddled. I feel the devastation that a mother must feel, looking at her sick baby through glass. I feel the terror and desperation that in infant must feel lying in a cold, hard, bright, box after being in his mother's warm, dark, safe womb. I weep.

That was my first visit to the neonatal intensive care unit in 1972. In the five years that I worked in the hospital I visited the nursery almost every day and sometimes several times a day. It did get easier. I became more aware of the human elements that made up running of the nursery. I saw the joys and tragedies of life played out. But I never got so used to being there that I did not have a twinge of pain each time I entered those doors.

And I was a staff person. My three sons were happily and healthily waiting for me to come home and cook them dinner or take them to basketball practice. How must parents feel entering the nursery for the first time, when it is their baby that is in the isolette? When it is their baby that is no bigger than their hand? When it is their baby that is seriously ill?

PREFACE

This monograph addresses some of the specific problems related to counseling parents of defective newborns. It describes the experience of the writer over a five year period, 1972-1977, in the neonatal unit of Goergetown University Hospital, Washington, D.C. During this period approximately two hundred fifty parents of defective newborns and may times that number of parent of children with lesser problems, utilized the hospital's services. My direct counselin g experience was with thirty of these parents during the process of making the very difficult decisions about continuing support care for their critically ill infants.

At Georgetown I worked intimately with Dr. David Abramson, Chief of Neonatology. Over a period of three years, we formulated the method of working with parents described in this monograph. We also worked closely with Dr. Mary Kate Davitt, who became the Chief of Neonatology after Dr. Abramson left. Together Drs. Abramson, Davitt and myself conferred in great detail about what we were trying to do with parents and how best to accomplish it. Our clinical findings about what happens psychologically to parents of defective newborns, and what can be done to help them are very similar to the scientific findings of Klaus and Kennell (1977).

In 1975 Dr. Abramson and I met with two ethicists who were interested in this decision making process, Richard McCormick, sj, and John C. Fletcher, Ph.D. These meetings stimulated our thinking and improved our work with parents. In addition I worked closely with staff, residents, students, doctors and nurses.

I also taught counseling parents of defective newborns to medical students, learning much from these meetings. During these years I had the opportunity to speak with many other professionals both at Georgetown and at other hospitals such as Columbia Hospital for Women, (Washington,D.C.), Fairfax Hospital (Virginia), Eastern Maine Medical Center (Bangor) and Grace New Haven Hospital (Connecticut), regarding this subject.

Interviews and case studies were my major research techniques. I interviewed five neonatologists, ten pediatricians, five residents, ten nurses and eight clergy. I interviewed five sets of parents and two mothers for their retrospective views of the process they had been through with their defective newborns.

I am grateful to all the parents who were willing to share their thoughts and feelings with me. I am grateful to all the professionals who related their thoughts on the issues of ethics, their feelings about illness, death and dying and their counseling of parents. I am particularly grateful to Dr. Raymond Duff for his help and support. I am also grateful to my special friends and colleagues, Susan Bradford, Catherine Bell and Patricia McHenry for their help and support in writing this paper. Dr. Georgia Fuller gave me support and help, particularly with the chapter on religion, for which I am grateful.

From these years of counseling, teaching, discussing and interviewing, I formulated ideas about what other professionals needs to know about the counseling process. They are presented in this monograph for physicians, social workers, nurses, counselors, clergy, and students, and others in this field.

To summarize the dilemmas these professionals have faced, the psychological and social problems of parents of defective newborns have been stated in the literature but suggestions for solving their problems have not been forthcoming. Parents of defective newborns have a greater separation and divorce rate than the average couple. Parents are often depressed and angry with little or no way to get help with these feelings. Problems with the couples' intimate relationships and problems which include the siblings and extended family usually arise as well. Parents often go through a religious crisis which so far has not been discussed in the literature.

In addition, little has been written about the moral and psychological problems felt by the physicians and nurses who care for these infants and their parents. There is a large turnover of nurses in the neonatal unit because of the severe psychological and physical pressure. The average "life-span" (job span actually) of a neonatologist is only four to five years. This pressure relates to what I call the "humanization of the health care professional." Doctors and nurses must be in touch with their own human, emotional reality before they can effectively help parents in emotional situations. Doctors and nurses must be in touch with their own feelings about the entire situation--infant, parents, ethics, religion and society--before they can most effectively help parents deal with their feelings about these issues. Doctors and nurses must be in touch with their own mortality and have dealt with at least some of their feelings about their own death. Current medical training does not address this "humanization" problem. For example, several doctors admitted that they feared their own death and that was one reason they were in medicine.*

In this monograph I will share the ways we found to help parents suffering the crisis of a defective newborn. It is by no means meant as a rigid formula. Each hospital and staff are different and must make their own adaptations.

All parents' names are changed to protect their anonymity. The residents and nurses that I interviewed did not want their names used, therefore, are recognized only as resident or nurse.

C. Dilworth,** a poet, philosopher and friend, who taught me much about living and dying, wrote these words shortly before his death:

> ...There is one week of silence over our village
> ...For some few it may be a private silence forever
> ...Two births do not take the place of one who passes
> through our village...in the loneliness of dying.

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* Personal interview with three physicians

** Bird (pseudonym for C. Dilworth), Many Mourners, Circle, March 17, 1975

CHAPTER 1

INTRODUCTION TO THE PROBLEM

Only a few short years ago general practitioners took care of most babies. If an infant was born into the world too early or had a disease or a serious malfunction, chances were very slim that the child would survive. Today there are specialists who care for infants in the first twenty-eight days of life called neonatologists and specialists in fetal development and disease called perinatologists.

Some of the recent advances of this caring for the human neonate are: prenatal diagnosis, amniocentesis, genetic screening and counseling. For example, doctors can diagnose some problems, such as Down's syndrome by amniocentesis. This and certain other genetic diseases can be detected by sampling the amniotic fluid surrounding the fetus and examining the chromosomes it contains for possible abnormalities. If an abnormality is discovered, the parents can chose a relatively safe abortion. Genetic screening and genetic counseling are other new and growing options. Genetic sciences often can determine parents' chances of having another defective infant in order to help them plan their future childbearing.

Today a mother in labor can have her baby monitored. Labor is difficult for any baby. If the labor is long or particularly hard, the baby may suffer. Even in what appears to be a normal labor, a baby may get into physical trouble. These problems can often be detected through fetal monitoring, and, if necessary, the physician can try to deliver the baby quickly, before any long term damage occurs.

In large hospitals where a neonatal unit and a neonatologist are available, a member of that unit is present at the birth of an infant if a problem is suspected or known. For instance, if a mother is having a difficult labor or if anything goes wrong during labor, a pediatrician or neonatal resident is called. Such a specialist is also present if the baby is premature, if a twin birth is expected of if the mother has a disease like diabetes or a history of disease or defect in a previous child. As an extra precaution, the delivery room can be equipped with emergency devices for suction, resuscitation and heat and with drugs.

After the birth of a troubled or defective newborn, the infant is rushed to an isolette in the neonatal intensive care unit. The isolette keeps out germs and adjusts the air temperature and humidity. It has respirators to ventilate tiny lungs which do not ventilate on their own. There are machines which record heart function, sounding an alarm if the infant's heart fails. There are intravenous feeding devices and new scientific liquids for better nutrition. Additionally, specialists, nurses, doctors, technicians, oversee tests, care for the babies and maintain the special machines and equipment.

Advances in this new age of neonatal medicine have made it possible to save the lives of babies who would have died only a few months ago. In some instances this is wonderful, a blessing to the parents and to the infant. In other instances children may be saved who are left with dreadful handicaps, both physical and mental.

> Survivors of these units may be healthy, and their parents grateful, but some infants continue to suffer from such conditions as chronic cardiopulmonary disease,

> short bowel syndrome or various manifestations of brain damage; others are severely handicapped by a myriad of congenital malformations that in previous times would have resulted in early death.
> (Duff and Campbell 1973: 890)

An example is children born with spina bifida. In Britain in the mid-sixties infants with spina bifida were vigorously treated with some disasterous results, such as the prolonged suffering of hydrocephalics and infants and children who are exposed to serious painful operative procedures who remained hopelessly crippled and mentally deficient (Lorber 1971). Later a system of selection was used and the severe cases were not treated (I. Lorber 1974).

1.1. What Is A Handicapping Condition?

What is a handicapping condition and how prevalent is it in our society? It has been defined by the American Public Health Association.

> A child is to be considered handicapped if he cannot within limits play, learn, work or do things other children of his age can do; if he is hindered in achieving his full physical, mental and social potentialities. The initial disability may be very mild or hardly noticeable, but potentially handicapping, or it may seriously involve several areas of function with the probability of lifelong impairment. The problem may appear to be primarily physical or perhaps emotional or social. Regardless of the nature of the chief manifestations, physical, emotional and social components are all factors at one time or another and in varying degrees, in most handicapping conditions of childhood.
> (Abramson et al. 1977:1)

As reported by McIntosh et al. (1954), the incidence of congenital abnormalities among six thousand fifty-three deliveries at the Sloan Hospital in New York City was seven and four-tenths percent for live births. (Abramson et al. 1977; Klaus and Kennell 1976). Klaus and

Kennell (1976) write that there are two defective newborns born for every two hundred births. This is not an uncommon occurrence and almost every physician or nurse will come in contact with a defective newborn during their own practice.

1.2. Cost?

The economic costs of fetal and perinatal casualties are felt several ways:

1. The cost of special services for the disabled: casefinding, medical, health, educational, vocational, transportation, recreational, hospital, institutional, etc;
2. The loss of income to the community resulting from loss of life;
3. The loss or reduction of income to the individual and the loss or reduction of productivity to the community;
4. The cost of support of the disabled individual by the family or community.

As summarized by Abramson et al.:

> It has been estimated that it costs almost thirteen billion annually to care for individuals with major chronic neurological and sensory disorder. (1977:19)

(For a breakdown of cost, see Abramson,et al.1977, Economic Costs of Fetal Perinatal Casualties, Chapter 2, Volume 3.)

As we will discuss in section 4.2. of this chapter, some ethicists believe the high costs of caring for severely handicapped individuals uses money which is better spent on other individuals or for medical research. A society has a finite amount of financial resources. The portion used to support severely retarded or physically defective individuals is not available for people who could perhaps benefit more. It may cost $10,000 to keep a severely damaged preterm infant alive for only three weeks.* Who pays this bill? We all do, for example, through insurance premiums or other forms of aid. Of course, the problem is more extreme for the individual family because insurance or other and does not usually cover all the medical expenses.** For a partially disabled individual with a neurological or sensory disorder, for example, the cost is $500 per year for physicians' fees and special management. For a totally disabled individual cared for at home the estimated cost is $2,000 (Abramson, et al. 1977). When related costs, like car fare, special baby-sitters and loss of work time is added, the price is debilitating for many families.

1.3. Sociological Consequences

What are the sociological consequences of saving the lives of infants who would otherwise have died usually quickly and fairly painlessly? They are twofold. First, as discussed in the previous section, there are financial consequences for the society and the family. Second, there are social and psychological costs. These financial and social and psychological costs are qualitatively similar to those of caring for children with a more minor defect, except that the resources of family and society are not as drained.

The problems most often encountered by the parents of defective children are: marital disharmony, depressive symptoms, suicidal impulses and psychosomatic symptoms.

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*Personal interview with family in 1976

**Personal interviews with five families caring for handicapped children

> The child's impairment may appear to be accepted, yet the parent may present to the general public inexplicable deepening depressive symptoms, marital tension, obsessional house proudness, chronic irritability, or psychosomatic symptoms. (Bentovim 1972: 581)

> ...in the majority of families there was disruption to a major or minor degree of their psychological or social life...More than half of the mothers had some symptoms of psychological disturbance, the most common being depression. (Dorner 1971: 25-26)

> Paradoxically, trauma such as the birth of a defective baby tends to magnify the weakness in a marriage more than it enhances the strengths of the relationship, and success, such as the easy birth of a normal baby will more often magnify or make more explicity the strenghts of the marriage. (Klaus and Kennell 1977: 178)

> Marriage [sexual] relations are not what they used to be. I would be terrified of having another child like this*

> The stress and strain of having a child with multiple congenital defects can have such drastic effects on parents that they may turn against their child resulting in battered child syndrome or maternal deprivation. (Klaus and Kennell 1977: 160)

Similar work was done earlier by Schild (1964) and Walker, Thomas Russell (1971).

1.4. The Ethical Climate

The technical saving of the life of a severely defective newborn causes many ethical as well as real life problems. Technology has saved many people with positive results. However, many of us know someone whose needless suffering has been prolonged by modern technology.

> Due to the amazing successes of medical science and technology, physicians are now able to keep the body

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*Personal interview, 1977, with mother

> functioning long past its natural span, long after the mind and spirit have ceased to exist, sometimes almost indefinitely by artificial means. They can produce what some have called a living death, or as David Hendin has said, "Dying is rendered obscene by technology. (Russell 1975: 15)

While Russell was writing about adults, the same can be said for infants born with severe defects.

Modern treatment of deformed and damaged infants has emerged from centuries of human experience. John C. Fletcher (1976) studied the record of humanity's struggle and divided his findings into three eras: prescientific; modern; and post modern.

In the prescientific era infants that were not normal were often disposed of. Infanticide was practiced in all sections of the world. The modern era was based on a modern understanding of environmental and genetic causes of birth defects. In the modern era infants were treated with all the technology that medicine could muster. Additionally, Christianity influenced care of the sick and suffering. We are now in a post modern era conditioned by new technology and new knowledge. This supports a new attitude which combines prevention of birth defects and selective treatment of those infants born with defects.

Thus, in the post modern era, the ethical problem of whether to treat all infants born with defects emerges. There are differences of opinion among lay people, nurses, doctors and ethicists. We are living in a morally pluralistic society. The two polarities can be stated simply as choice and no choice. A number or primary values are being defended in this debate by ethicists and non-ethicists alike.

1.4.1. Six Abstracted Values

There are six basic values being defended by the debate concerning defective newborns as abstracted by Weber (1976). The two most common abstractions are: the least possible suffering ethic and the protection of life ethic. Let us examine these two positions first.

The protection of life ethic is perhaps the most well known. Defenders might say, "Life is precious. What right do we have to make decisions on life or death matters? We have an obligation to protect all life, whatever that may be." Usually this is linked with "We cannot play God."

The Least possible suffering ethic is the other major abstraction. Supporters believe that suffering is the important component. If a person is suffering badly, it is all right to allow the person to die. If the person does not die quickly enough it might be better to help the person to die than to allow suffering. It is different to kill out of malice than to kill to relieve suffering.

There are four other minor positions defended in this debate.

The welfare of society ethic. This stance is concerned with humanity's common good. "There are just so many resources in a society and we cannot keep unproductive members alive. We must be practical."

Survival of the fittest is the next position. Defenders might say, "Nature's way is simple; only the most healthy survive." Those who are defective do not survive. "We must think in terms of the evolutionary process and not allow the species to become weakened."

The fifth position could be called, *freedom of conscience*. These people might feel, "I cannot tell anyone else what is right or wrong for them. What is right for me might be different for them. I would not want anyone telling me what to do nor would I tell anyone else what to do.

The last position is, *sufficient mental capacity*. It uses the level of mental processes to help decide who shall live. For these people it is not really living to be a mental infant all one's life. Human life was not meant to be that way. "It is foolish to treat a child who cannot attain some level of educability."

Many doctors, nurses and parents, who are making decisions about defective infants, seem to use different aspects of these abstracted positions to come to their concrete conclusions. It is very difficult for them to make these decisions when the ethical experts differ so much among themselves. It is simportant for us to consider what some of the well-known thinkers have to say about decision making regarding the defective neonate. With this as a basis of understanding, we may better help parents with their decisions. Accordingly we have chosen four ethicists who span the major aspects of this debate, propounding different configurations of the six values abstracted by Weber. They are David Smith, Joseph Fletcher, Warren Reich and Richard McCormick.

1.4.2. Four Ethicists

Smith (1974(thinks that something must be done to preserve the life of every defective newborn. He feels that there is little difference between an act of killing and an act of withholding care if it results in death. However, he makes an exception if killing directly preserves the life of another person. While it is sometimes permissible to kill a person who is beyond human love, Smith feels that a handicapped infant is not beyond human love and therefore must be cared for. It is our moral obligation. However, Smith further "argues that this obligation does not mean always doing everything possible to cure, but doing something in an attempt to cure. " (Weber 1976:62)

Joseph Fletcher argues a different position. (Bennett et al. 1967) Infants who will never be capable of truly human functions are not human. To allow them to die or to kill them is not killing a human person. He oppose those who "absolutize mere biological life," arguing that life is not automatically sacred just because it was born of woman. Instead Fletcher focuses on the quality of life as well as the degree of suffering as important points in the decision to let die or to kill a deformed child. In some cases putting to death is the most humane treatment.

The ground between these two positions is wide. Parts of this intermediate ground is defined in the writing of Reich and McCormick. Reich (1973) thinks that there is a difference between withholding treatment and directly killing. Letting an infant die is proper at times; killing is not. He disagrees with Smith, that every child must be treated. He also disagrees with Fletcher, that some lives are not as valuable as others.

Reich summarized his position by commenting on a well-known case of a defective newborn who had spina bifida with meningomyelocele:

> I believe that in some instances extra ordinary means may be omitted in pediatric care, even if this means the newborn will die. This means that, in a case such as Missy's, full and adequate treatment should normally be given the newborn, but that in some instances, when the prognosis is very poor, it may legitimately be decided that surgery and other subsequent exceptional treatment should not be performed, and that only supportive care be given. (Weber 1976: 66)

Reich concluded that extraordinary means do not have to be used if there is little hope of success. This requires a judgment on the "Quality of life."

The final representative ethicist is McCormick. In an important essay published in 1974, McCormick states:

> The guideline is the potential for human relationships associated with the infant's condition. If that potential is simply non-existant or would be utterly submerged and undeveloped in the mere struggle to survive, that life has achieved it potential. There are those who will want to continue to say that some terribly deformed infants may be allowed to die because no extraordinary means need to be used. Fair enough. But they should realize that the term "extraordinary" has been so relativized to the condition of the patient that it is this condition that is decisive. The means is extraordinary because the infant's condition is extraordinary. And if that is so, we must face this fact head-on and discover the substantive standard that allows us to say this of some infnts, but not of others. (Weber 1976: 68)

McCormick places great value on the individual but measures that value in terms of the quality of life. In this citation he is proposing that when a child, even with treatment, will never have a potential for human relationships, it is appropriate to withhold treatment and allow him or her to die. He thinks that certain treatment may be refused, because it would lead to a life devoid of the things which can make a life human, such as, giving and receiving love. Treatment may also be refused if it would lead to excessive hardship for the individual such as pain or undue suffering. It make no sense to pursue a life when the basic purpose of life, human relationships, cannot be achieved.

These are the positions being held by some of the leading thinkers in the field of medical ethics in the United States today. They do not agree and this we must keep in mind when dealing with these problems ourselves. Others of importance who have written about the problems of choice with particular reference to the newborn are Raymond Duff and A.G.M. Campbell, Anthony Shaw and John C. Fletcher.

1.4.3. Laws and Practice

There is another important aspect of the larger issue of treating newborns--the legal climate in our country, and the world regarding infant euthanasia. The law concerning decision making for defective newborns is antiquated, with even the legal system ignoring current laws in favor of what is becoming standard medical practice--the decision is not to treat certain seriously defective newborns. Robertson (1975) writes that the legal climate is one of non-enforceable laws. Additionally, the legal system has ignored certain cases of withdrawal of treatment, thereby permitting physicians and parents to make decisions about euthanasia. The difficulty for people who must make these decisions is that they are left in limbo. Robertson suggests a need for laws which will help us with these profound problems. (For further study, see: John A. Robertson's, "Involuntary Euthanasia of Defective Newborns: A Legal Analysis," in Stanford Law Review, Volume 27, Number 2, January 1975.)

Although there are two basic positions with intermediate points among the ethicists,represented here by Smith and Fletcher, there is relative concensus among the medical practitioners. It is, however, more informal than formal. It tends toward trying to save the badly damaged infant while steering away from selection, although it does not shrink from decision to withhold support from a baby who is hopelessly damaged. Here in the United States there is a tendency to ask parents to be a part of the decision making process for their child. In England, by contrast, the criteria of selection are based upon the standard set out by the medical profession. There seems to be little involvement with the parents in this decision making process. (Lorber 1971; Lorber 1973)

American physicians-philosophers, Raymond S. Duff and A.G.M. Campbell (1973) have written courageously about the grave moral and ethical dilemmas faced in the special care nursery. They have brought out in the open the decision making process that has been hidden from society. In a later paper, "On Deciding the Care of Severely Handicapped or Dying Person: With Particular Reference to Infants" Duff and Campbell (1976) wrote that parents and family are the logical people to decide for the infant because they are the closest people to the infant. Parents, especially, care about the infant more than any outside person,and they will be most affected by the outcome of the illness or death. Our experience causes us to agree with Duff and Campbell.

If parents are going to participate in the decision making for caring of their newborn, as we believe they should be, what is the process they go through to reach that decision? What are the psychological ramifications of giving birth to an infant who is defective? What happens to parents faced with the decision to stop or to continue support care of a severely defective newborn? This study concerns the care of the defective newborn and counseling the parents--an aspect of neonatology that has been neglected. Most papers are descriptive in nature, such as: "Counseling with Parents of Retarded Children Living at Home" (Schild 1964); "Spina Bifida and the Parents" (Walker, Thomas and Russell 1971) and "Spina Bifida Cystica and Family Stress" (Hare et al. 1966). These papers describe the problems while giving us little help for the solving ofthem. For example, the literature states over and over that mothers are depressed but does not suggest how to help a mother out of her depression. The literature states agains and again that marital relations are under stress, but does not suggest how to work with mothers and fathers to relieve their tensions and allow communication to resume, or in some cases, to begin.

This is the area addressed in the following chapters. We will write about the counseling process we have used successfully with the parents we encountered.

CHAPTER 2

REACTIONS OF PARENTS AFTER GIVING BIRTH TO A DEFECTIVE NEWBORN

2.1. Background

For couples who are expecting, the period of pregnancy is usually an exciting, wonderful, miraculous time. Even if the pregnancy was not planned, usually by five or six months they bein to anticipate the birth of their child. Parents all expect the child they are awating to be normal, at the very least. Most expect their idealized baby, beautiful, bright and happy, ready to fulfill their fantasies of what a baby should be. (Klaus and Kennell 1976)

Having a child is the closest, most realistic route to immortality. (Lifton and Olson 1974) Therefore, a child may take on more meaning for parents than that of simply a child. With the birth of a defective newborn there is immediately an intense crisis. Parents feel numbness, grief, distrust, waves of helplessness, rage and disbelief. The expected, perfect child is lost, the feared, defective, damaged child is born. Parents may feel that they want to get rid of the damaged child; let it die or kill it. They must deal with the different mixtures of fear, anxiety, guilt and shame that their intense feelings produce. (Bentovim 1972)

John C. Fletcher states in his paper "Spina Bifida with Meningomylocele: Case Study of Attitudes Toward Defective Newborns":

> I am convinced that the initial universally negative reaction to the defective new born unites all participants in confrontation with

> the terror of death and even in the sublime moment of birth. (n.d.: 23)

Perhaps this is one explanation for the severity of the reactions most people face with the birth of a defective newborn. And it is not the parents of the child alone that have severe reactions. The extended family as well as nurses and most who come in contact with the child react in passionate ways. While all concerned are intensely touched by the birth of a defective newborn, often those people who need help the most, the parents, are overlooked or inadequately helped.

As we have discussed previously, "In the United States the birth of an infant with a major malformation occurs in two of every one hundred births. Thus almost every nurse or physician will have a part in the care of these babies." (Klaus and Kennell 1977: 168). Because of this doctors and nurses need to be more aware of the problems parents face. One of these is shock. Most parents have told me that even though they had worries and fears about something being wrong with their child, they never really expected it to happen.

Counseling skills combined with human warmth, empathy and time freely spent are basically what is needed to help parents through their crisis. Some parents will need less time and energy than others based upon their individual needs and the severity of the illness or defect of their child. Each parent has his or her own worries and fears and we must be attentive to the individual need, as well as the specific problem. What may seem a small problem to a resident, who perhaps has three babies on respirators, is paramount to the parents of each child.

Because parents are unique, each may be expected to react in his or her own specific way. There can be no formula which the counselor follows rigorously. The following suggestions help unravel the uniqueness of each situation:

1. Who are the parents?
2. What are their feelings?
3. What else is going on in their lives to affect their feelings? (For example, is the mother's father dying of cancer?)
4. How do they relate to one another?
5. What is their socio-economic situation?
6. Did they want this child?
7. Are there other children in the family?
8. Have they ever lost a child before?

Many similar questions relevant to their lives should be asked. The more the counselor is available to the parents and honest with them, the more forthcoming these answers will be.

The counselor must additionally be aware that medical personnel are not likely to be alert to the psychological factors outlined above. Rather they tend to be uncomfortable around parents who are intensely emotional and often steer clear of them. The following are examples:

> The staff devoted more energy to making arrangements for the transfer of the child for surgical care than they did to dealing with the shocked bewilderment of the parents. (Walker, Thomas and Russell 1971: 465-66)

> These parents appeared to feel not so much that they should have been given further instruction, but that the doctor or nurse didn't seem to appreciate the worries and anxieiteis the parents had to bear and didn't say the simple workd of comfort which would have indicated their sympathy and understanding.(Hare et al. 1966: 758)

> It is important to add, that to talk with angry or depressed parents is not the natural inclination of the obstetrician, pediatrician, or registered nurse. The gratifications of these professionals lie in either the delivery and care of the healthy infant or in the use of their medical knowledge to heal or remedy. With a congenitally malformed baby they are often helpless and therefore feel useless. This of course is not so and although at the time it is not evident that extra visiting is doing any good, it is important to visit repeatedly and not abandon the mother to her grief. (Klaus and Kennell 1976: 177)

Modern hospitals have too often gotten away from the simple comforts of human contact that parents need. Sharing feelings and openness through the sharing of sympathetic and empathetic feelings cannot be stressed enough. I have never known a doctor or nurse who is deliberately mean or who deliberately withholds what a mother needs in time of crisis. The majority simply miss the mark because of fear or lack of knowledge and understanding. This is illustrated by the following incident from our observations:

> A mother approached the resident seated inside the neonatal intensive care unit. "Doctor," she inquired, "I'd like to know if the circumcision that will be done on my baby will hurt him. I'm worried about it."
>
> The doctor replied without really looking up from his reading, "Don't worry, babies can't feel it. The procedure is strictly routine." The mother walked slowly away still looking worried.

This mother wanted and needed more than a brush off. She was obviously concerned about her baby and wanted to talk about the procedure. She probably thought the resident would give her human contact as well as an honest, professional answer. We might ask ourselves, "What are the unspoken questions that this mother has? How did her husband feel about having the procedure carried out?"

In our own experience, parents often differ in their desires about circumcision of their son. The mothers often have read some of the latest literature which states that circumcision is no longer recommended as a routine procedure. They usually have intense maternal, protective instincts which made it very difficult for them to allow their sons to be hurt. The fathers, on the other hand, generally want their sons to be like themselves and most men they know. This simple inquiry could have serious implications to the lives of the parents who present it.

Another difficulty in relating to parents is that medical professionals frequently lack perception and misinterpret normal distress behavior. For example we received the following advice:

> I think perhaps we should get a psychiatric consult on Mr. Wilson. He sat here all night with his baby and and he cried off and on all night. [Mr. Wilson's baby was in serious condition in the neonatal intensive care unit.]

In checking with the nurses and the resident who believed that a psychiatric consultation was in order, we discovered that in fact the father had not displayed inappropriate behavior. He had simply sat and talked to his son throughout the night and at times wept. We consider this healthy and thoroughly appropriate behavior for a man sitting with a son who was expected to die. The resident and some of the nurses were simply uncomfortable with someone who was so openly showing his feelings. The nurses found it even harder to accept because the person was man.

In some extreme situations, neither the obstetrician nor the attending nurse can be relied on to provide help to grieving parents. An example of our case studies shows:

> Mr. and Mrs. Jones gave birth to an infant with multiple congenital abnormalities. The baby died within twenty minutes after being rushed to the intensive care unit. Neither parent saw the baby in the delivery room. A nurse told Mrs. Jones to "calm down;" that she needed to take care of herself. The nurse appeared very frightened. The obstetrician immediately left the hospital, leaving the job of talking to the parents to the neonatologist who was a stranger to them. He did, however, order a private room for them but released them early the next morning before the pediatric staff or a counselor could see them.

What happened here and why? The nurse, who was herself frightened by the severity of the situation handled the mother the only way she knew how, by telling her to "calm down." She was trying to put her own world back into a familiar perspective. Mrs. Jones' obstetrician left the hospital as soon as he could. This is not an unusual response for physicians after the birth of a severely defective newborn. One obstetrician told me:

> I feel somewhat guilty, when one of my patients has a severe problem. I know I'm not to blame in these cases, but parents have unspoken expectations that I should deliver a health child, and I want to deliver a healthy child. It is hard to face them when their child is not healthy.*

It is important for nurses to realize that they can stay with an hysterical mother--even when they do not know how to handle the situation. Just being there is almost always a comfort. It is important for obstetricians to realize that they are the only people the parents knew before entering the hospital. Obstetricians can be their friends by simple sharing the shock and sadness of the stricken parents. It is important for the staff to realize that

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* Personal interview with an obstetrician

parents who do not see their dedad newborn have a more difficult time going through the mourning process.(Klaus and Kennell 1976).

Imagine this. A mother feels her newborn child moving inside her body for months prior to the birth. She plans for and fantasies about the child she is carrying. She goes into labor, her baby is born, but suddenly her child is rushed from her never to be seen. Someone inform the praents, "I'm sorry, your baby has died." How must they feel? How difficult will it be to accept that the fantasy child is not to be? Parents tend to think and imagine worse things about their unseen child than may be present.

We can offer these parents the possibility of seeing, touching, and being with the dead infant. Perhaps we could say something like:

> Some parents whose child has died want to see their baby, others do not, it is up to you. If you would like to see your baby we can arrange a private place for you to do that. Some parents have found it helpful to be with their baby, maybe to say goodbye. It doesn't have to be right away. A little later would be fine. Think it over and let us know. I will be back in an hour or two to see how you are doing.

2.2. Adjustment Pattern Of Parents of Defective Newborns

We have observed a pattern of mourning that parents of defective newborns go through. It is very much like the pattern of mourning for the death of a loved one as described by Elizabeth Kubler-Ross. Parents typically have an image of their hoped for child which they have been nourishing for several months. Suddenly <u>another</u> child is born; one that was not anticipated nor dreamt about. The less than perfect child takes the place of their fantasy child. Something has to happen in order for the parents to accept this new and different child. The parents must actually give up the hoped for child by mourning the fantasy existence.

We have observed that parents go through surprisingly similar states in their emotional reactions, whether their child's defect was considered minor or major. Although the amount of time needed for parents to deal with the stages remained fairly predictable. Some parent might skip over a stage or deny emotions related to a particular stage. At a later time they usually return to what had been missed.

The following is a hypothetical model of normal parental reactions to the birth of a child with congenital malformations. (Drobar et al. 1975: 710-717)

Relative Time Duration

I. Shock; II. Denial; III. Sadness and anger; Iv. Equilibrium;
V. Reorganization

Klaus and Kennell (1976) report findings similar to the aforementioned graph. It has been our experience as well that these are the basic stages parents go through when confronted with the birth of a defective newborn.

First State: Shock

Most parents' initial response is one of overpowering shock. One mother said, "I worried about something going wrong during pregnancy, but I never in a million years thought that this would happen." Another mother said,"I'm just numb; I can't feel anything." A father told me, "I'm shocked, I don't know what to do." Parents often act irrationally. There may be outbursts of violent crying and feelings of helplessness. Going numb or feeling nothing seems to be characteristic of the initial shock. It is as if a person' circuits are overloaded and they simply short out. The news that their baby has a congenital abnormality is too much to handle at one time so that the going numb is a way to shut out pain.

Stanly Keleman in Your Body Speaks Its Mind (1975) describes a similar phenomenon which he calls being startled or surprised. When a person is startled there is a pause before he commits himself to do anything. He says, "A child who falls down hard always braces himself before screaming." The numbness that parents describe might well be like the bracing up before allowing the painful feelings to flow.

Second Stage: Disbelief and Denial

Most parents go through a stage of trying to avoid or deny that their child has an abnormality. It is during this stage that parents want to run away. One mother said, "I just want to get away and forget this whole thing." A father said, "I though, this can't be true, I can't have a child like this." Parents often stated that they just couldn't believe that it could be happening. Klaus and Kennell (1977) warn us that during this stage parents may want to try other doctors, other cures. They simply do not want to admit that there is no cure for their child.

We have alos observed parents becoming very religious at this time. "I keep praying for a miracle," one mother said. Parents may try making a deal with God at this point: "I promise to go to church every day for the rest of my life if you [God] will cure our baby." One mother reported trying this approach.

Third Stage: Sadness, Anger, and Anxiety

Most common at this stage were feelings of acute sadness. Parents report feeling uncontrollably sad. One mother said, "Tears would just start flowing from what seemed like nowhere." Both mothers and fathers reported feelings of depression, feeling blue, feeling no energy, feeling down. Men who were less able to outwardly show sadness by crying were more likely to become unusually quiet and withdrawn. One father disappeared to the cellar where he began working diligently on various projects in his workshop. We are concerned about parents when they became withdrawn and depressed or cannot show their sadness outwardly to one another. Those parents have more difficulty moving on to the next stage in the process. One mother who continued to withdraw and deny reality was hospitalized. There is the psychiatric ward she was taken care of and felt safe enough to let down and feel the devastating reality that she had a deformed child. After only a few days she could begin to cope with her life again.

Every parent that we worked with felt anger at some point. Fathers were more likely to recognize their anger because anger is an acceptable emotion for men in our society. Mothers, however, usually tended to hide their anger with sadness or frustration. When the time is right it is helpful to encourage the feelings of anger to be expressed and assure parents that this was a normal reaction.

One father told us of being overly severe with his three year old at home. He had not realized that it was related to his anger and frustration about his baby. Another father told us, "I want to break things. I feel like taking this chair and ripping it apart." Sometimes we suggest to parents that they hit or kick the bed at home and to verbalize their frustrations at the same time. I'm convinced that this can save many an innocent three year old from a wrath that he should not have to endure; especially at a time when Mommy and Daddy are away a lot and are otherwise preoccupied. Often anger was expressed at the doctor, the nurses or the counselor. Whoever is working with parents needs to be aware of this and help parents through this period without getting defensive. Sometimes this is a difficult task when parents are furious with you. Anger was also expressed almost universally at God. (See chapter 5.)

Parents have expressed their anxiety that the baby would die even though they are assured otherwise. We have found this to be a real fear. However, sometimes it covers up a parent's desire to have their baby die. There is usually ambivalence at this point. "I want my baby, the fantasy child, I don't want this baby, the defective child." Expressing this wish for the baby's death is difficult because one is not supposed to wish his child dead. There is a great deal of guilt around these feelings. It is helpful to express this wish and to get it out in the open. Once out in the open negative emotions lose their hold on us. Parents are told that this is a common feeling and that we all can feel two ways, even about a person. We can both love and hate a husband or wife, loving most of the time and occasionally becoming furious enough to have the fantasy of killing, choking or kicking the partner. It is important for the parent having this feeling not to feel like a bad person.

Finally, parents have reported that not only do they feel anxious about the newborn's life,they may become anxious about other children at home. One mother told me, "I began to worry about Bobby at home. I worried that he would be hurt or killed in the most horrible ways." From our experience, we have added this emotion to the third stage.

Fourth Stage: Equilibrium

Gradually intense feelings of fear, anger and sadness lessen. For some parents this takes weeks,for others many months. Parents that they begin to notice the world outside themselves. "When I drove to the hospital today I noticed the flowers were blooming and they looked nice," said one mother after six weeks of living in a world entirely made up of herself and her sick child. With parents who must live with a child who is sick or defective, their sadness continues in some way even after years. Perhaps it will never diminish completely. (Klaus and Kennell 1976)

Fifth Stage: Reorganization

During the stage of reorganization parents begin to deal with the real world problems of their responsibilities to their handicapped child and how to manage them. This might involve planning for the baby's homecoming, seeking help in obtaining any special equipment that they might need to care for the child or planning for some future event. One set of parents began calling special schools to inquire about their child's future education. One father told us, "My parents have agreed to take care of Missy if we should both die. It takes a load off our minds because one of our biggest worries was what will become of Missy when we aren't around to care for her any longer?" One father inquired about the infant stimulation program at the hospital. This stage may last years as there are continuing changes in the life of the family and changes in the relationships between family members.

To summarize, parents go through stages of:

1. Shock
2. Denial
3. Sadness, Anger and Anxiety
4. Equilibrium
5. Reorganization

The way parents handle these stages varies considerably from person to person. We always must be on the alert when working with parents to be sure that we are treating them as individuals first. The pattern for their grief work should be well known but must take a back seat during the actual session. For example, some parents stay in the stage of shock longer than others, or will completely skip over the anger stage, having to go back to deal with it much later. Knowing these stages help the counselor introduce feelings which parents may be suppressing. The one we find most often suppressed is anger and particularly anger at God. (See Chapter 5.)

CHAPTER 3

PROBLEMS IN INITIATING A COUNSELING PROCESS

3.1. Dealing With Emotion

How many of us have been patients in a hospital or had family members in a hospital in the past years? Those who know that most hospitals are busy, fairly impersonal places. Nurses are basically trying to care for physical ills and to get all their work done. Doctors run in and out once a day and check a broken leg, a uterus, pneumonia or cancer. If we are sad, angry or confused about or because of our illness, we very rarely say so. Hospitals, we tell ourselves, take care of medical problems and psychiatrists take care of mental problems.

In truth, feelings were not acceptable things to express in the old hospital setting. Patients who had psychological pain were less understood than patients with physical pain. Physical pain could be more easily dealt with and did not involve the emotions of the staff people as much as psychological pain. Nurses told patients to "Keep a stiff upper lip," or "Why don't you think about something more pleasant." Attitudes and lack of positive help often told us: Don't feel--Pretend--Wait until you get home. Hospitals were not the appropriate places to be emotional. A mother tells of her experience 14 years ago.

> I just felt numb when the doctor told me that my baby had a club foot. For days I just pretended to be feeling fine. No one asked me how I felt or suggested that I might feel bewildered, sad or upset in any way. Finally I just locked myself in the bathroom and cried. I wasn't even sure why I was crying but one thing I did know was that I couldn't let anyone see me do it.*

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*Personal interview with a mother

A pediatrician tells us of his experience with feelings.

> I was working with a pediatric patient. A girl who was thirteen. She was dying of cancer. I would talk to her and hold all my feelings. Later I would go in the closet and cry. I didn't think I was supposed to have feelings like that. I had no one to talk to. Now things are getting better, some doctors are being taught that feelings are OK.*

We live in a drug oriented society. If we have a headache, we take aspirin; if we can't sleep, we take a sleeping pill; if we are too sleepy, we take something to wake us up. When it comes to the matter of emotions this is also the case. Too often the easy answer for an upset mother is a sleeping pill. On the maternity floor a nurse routinely asks a mother, "Do you want a pain pill, a sleeping pill, a dry up pill or a laxative today, Mrs. Smith?" This is offered to well mothers of well babies; mothers who are in the prime of life, experiencing the natural function of birth and lactation. If a mother is emotional after the birth of a sick or deformed infant, a tranquilizer is standard fare. Sometimes this is necessary of course. However, often it is done out of convenience or convention, because we are not used to strong emotions. We do not know how to handle them ourselves. They make us nervous and uncomfortable. We cannot wait to get away form a person who is exhibiting strong emotion.

> I went into the mother's room to see how she was. She was crying. I got very uncomfortable. I tried to say something consoling and then I just got out of there as fast as I could. I didn't know what to do.**

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* Personal interview with a pediatrician
** Personal interview with a nurse

These practices in the hospital reflect our whole cultural pattern. Men are taught to "be strong,""don't cry" and "act like a man." We are expected to hide most deep emotions, especially sadness and anger. We also avoid physical contact. Two men rarely walk arm in arm, as is common in some other countries. Although it is more common for women to touch, it si still rare, compared to other cultures. (See Hall 1973, especially chapter 10.) We pull back if we are brushed, or sometimes even approached within 10-12 inches. We too often ask people, including our impressionable children,"What do you think?" not "What do you feel?"

Our cultural pattern is changing. There is a new and strong interest in Eastern martial arts, exercise and meditation. The women's movement (and the small but growing men's movement) is challenging stereotypic male behaviors, like those cited above, and encouraging a greater expression of emotions, such as crying and anger, by men and women. People are becoming increasingly involved in natural vitamin, herbs and wholistic health. In medicine, in particular, we see a new trend that is trying to bring back the old skills of treating the whole body and its integration with the mind. For example, there has been an upsurge of interest in the ancient treatment of traditional Chinese acupuncture, a practice which approaches mind, body and spirit as one. In addition, there is greater practice of homeopathy, which also treats the mind and body together. From the other end of the health picture, bioenergetics is one of the many new methods of therapy which treats the body along with traditional analysis of the mind. (Lowen 1977) This is a time when more and more people are taking a wholistic approach to illness and health.

The wholistic approach works with more than an isolated diseased area of the body, such as a gall bladder. The emotional aspect of the patient is becoming recognized, even on the medical floor. More staff members are encouraged to talk to patients and to try to meet their emotional needs, although usually they are not taught how to do this. Hospitals now have social workers and counselors and there is often access to psychiatric consultation. Feelings are becoming appropriate on some hospital floors. We have come a long way but there is still much ground to cover. In the field of neonatal medicine the feelings of parents of defective newborns are still difficult for many doctors and nurses to understand and to cope with.

3.2. The Basic Problem

Just as counseling is fairly new in the hospital setting itself, counseling parents of sick or defective newborns is a new concept. It is even newer in terms of implementation. There are always problems involved with trying to implement change in any system. This area is no exception. When we started using the counseling model with parents, many problems, which might have been expected, emerged. Most relate to the basic philosophical differences between medical personnel and counselors.

The first problems we encountered arose because as counselors we were changing the unspoken rule that feelings should be kept hidden in the hospital. The "proper"way of acting was a little like going out to dinner at a fancy restaurant--act as if you are fully in control of yourself at all times. I continually heard the term "inappropriate behavior" used to describe a mother who cried or a father who lost control, even for a few minutes. Over and over I responded, "I would think it inappropriate behavior if the mother did not cry," or "I think it is totally appropriate for the father to lose control under these circumstances." I would often add, "I would worry if this mother was not crying," or "if this father was not angry."

Still, our program continued to receive complaints from nurses when parents would leave a session and go the nursery and cry. We had more complaints when parents would occasionally express anger at the doctor, the hospital, or the nurses. We met with the staff and listened to their feelings about these outbreaks of sadness, anger or other normal crisis emotions. We spent hours explaining the emotional stages, as discussed in chapter 2.2., and our efforts to help parents navigate these crisis stages.

Why did doctors and nurses find this new counseling model so difficult to accept? After talking with many doctors and nurses, I found that their training lacked counseling skills. Counseling skills were not taught in a practical or even theoretical manner to most medical people that I interviewed. Those that had theoretical knowledge found it too abstract to put into practice with any comfort or confidence. Medical schools traditionally reward and appreciate the medical and technical skills of their students. Humanistic skills--those of empathy, how to listen, or how to relate to another human being--were neither taught nor encouraged according to the professionals I interviewed. For example, doctors have said:

> We have no setup to talk to parents here. We have no one who has the time or qualifications to talk to parents...*
>
> I was never taught anything about this [counseling] in medical school.*
>
> People think doctors are born knowing how to deal with these emotional problems with patients...that automatically upon graduation from medical school we know just what to say. Not true. No one ever mentioned these problems [counseling parents] when I was in school...*
>
> I only talk to parents if there is something encouraging to tell them. If not, I walk the other way. I'm very uncomfortable.*

The writings of Kubler-Ross have brought the issue of death and dying out in the open. Some medical schools are now offering courses on death and dying. However, there is still, little, if practical, "how to" assistance for students on dealing with their own feelings about death or helping someone else through the process. Information in medical and nursing schools consists mostly of learning through readying or lecture material. The mind receives the information; the body and the emotions are not necessarily touched. Without the emotional learning students are left to experience it on their own, during clinical training or after they are in practice.

> I learned the long, slow, painful way...by making a lot of mistakes with parents.*

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*Personal interview with physicians

This brings us to the second, basic problem we encountered in setting up our counseling service. Several doctors told me that they had a fear of death. Two stated that this fear is one of the reasons that they pursued medicine as a career. They thought it would give them more control over illness and death, with a pervading notion that death is to be avoided at all costs. This notion creates a horrible monster which blocks any real or honest communication between doctors and dying patients or doctors and parents of very sick children. Dr. David Abramson, a neonatologist, describes his own emotional journey, through three stages in relating death.

> This whole subject was carefully avoided in training... but when I look back on the past ten years, I can see an evolution of myself and the way I relate to patients. At first I thought death was the enemy, and that my job as a doctor was to fight it and to avoid it as much as medical science gave me power to do so. When I was a resident, I began for the first time to participate in decisions to turn off the respirator, but I did it with a sense that death was inevitable, and I could reluctantly accept it when I could not do any more to stop it. This I feel was a compromise with death. The change in me began when I began having trouble and being anxious in relating to parents of very sick newborns. I couldn't sleep very well and was at times terrified by the decision I had to make. I began therapy and my eyes and my eyes were opened--that it was my own fear of death that was frightening me and getting in my way with the parents. I began to change when I was able to accept the fact that I, too, am going to die. Now I actually see that death is desirable for some babies, and I can face the decision in myself, that I want this particular baby to die, that is valid and a good outcome for me to work towards. I learned that I could not make good decisions about death until I had accepted death as part of life. I can come out from behind my professional role and share in the anger and loss of giving up to death. I could not do that earlier. (J.C. Fletcher 1975:76)

In summary, we must begin to scrutinize old ways of thinking and behaving in order to help ourselves and to help parents and

and patients deal with their experiences in the hospital, particularly those related to serious illness and death.

Proper behavior in a tragic situation does not come easily and awkward moments arise out of different conceptions of what is "proper." An illustration of this occurred after the death of a baby after a long illness. A decision had been made by the parents and the doctors that death would be the best outcome in this particular case. The parents had been with the baby and held her as she died, saying their private farewell to their well-loved child. Later in the day as I passed the nursery:

> One nurse cradled in her arms a green plastic garbage bag, the kind we rake our leaves into or put trash into and set out for the garbage truck to take away. The head nurse was scolding her, "No, No," she said, as she took the bag from her, "Hold it like this." She held it at her side, clutching the top as though it <u>were</u> garbage. "We don't want anyone to know what it <u>is</u>." The other nurse gingerly took the sack and walked down the hall. I stood there dumbfounded. There was a human body in the that sack--a beautiful girl infant. One for whom the parents were still grieving.

What had happened? Death is something that is feared and hidden. Have any of us ever seen a dead person in the hospital? Unusual, although people do die there quite often. Bodies are hidden from view and transported inconspicuously. This might be all right if they did not lose their humanhood in the action, and if the reasons behind this behavior were not unhealthy. Death is considered a failure by many doctors and nurses. It is still a difficult subject for most with whom we have worked. And because of this, most had difficulty at first in accepting our counseling work. Sandol Stoddard says in her new book <u>The Hospice Movement:</u>

> The death of a patient is perceived as a humiliation an an outrage by the average physician in our culture; to the nursing staff in an acute-care hospital, it feels like a personal defeat. To the patient's family it may very well represent the occasion for a malpractice suit. For indeed, why should such an untoward thing as death be allowed to happen in our society. (1978:1)

Somehow a forum must be created to sort out old fears and prejudices, to explore and express feelings and to give doctors and nurses an opportunity to learn and to deal realistically with the human issues which surround illness, death and working with parents of children who are ill or defective.

CHAPTER 4

THE COUNSELING PROCESS

4.1. Philosophy

We believe that a child for whom we are partly responsible is influenced by the total environment. If his parents are not healthy he is entering an unhealthy situation.

Our philosophy of care is based on the basic belief that to allow feelings to be openly expressed is therapeutic. We premise this philosophy on the basic teachings of Freudian psychology as well as many of the new, humanistic approaches to psychotherapy and body-psychotherapy (e.g. gestalt therapy, family therapy, bioenergetic analysis, transactional analysis, primal therapy and crisis intervention techniques). Feelings that are not expressed can cause both somatic and psychological problems. For example, held in feelings can cause anger or depression. The may become the seed of depression, as is so persuasively put in Alexander Lowen's Depression and the Body (1973). Further, unexpressed feelings may grow into extreme mental confusion and result in irrational or unrealistic behaviors.

In our clinical experience we often see parents confused about making a decision regarding their baby. Their feelings say one thing and their intellect says another. For example, I want my baby to die because it is best for her; I don't want my baby to die because it hurts me (emotionally) too much. If given support and time to express their feelings freely, parents usually put their thoughts and feelings together and come up with their true wish for their child's care--a wish that we can trust. We do not automatically approve the decisions of a parent. First we encourage them to do the emotional work that is necessary in making that decision. For example, if a parent simply says, "I don't want the respirator turned off," or "I want the respirator turned off," we ask about the process that both parents went through to reach their decision. Otherwise their deepest fears or true feelings might surface at a later date. In addition, the mother might favor one decision and the father another, without telling each other. After an action is taken in such cases, the marriage begins to deteriorate.

Our philosophy of care is one that treats the newborn and his or her family as a unit. Newborn infants cannot be cared for in a void because they are very much a part of the family unit whether that unit consists of: baby, mother and father; baby, mother, grandmother; or baby and a family of any size and description. Siblings are an important part of the family unit and are carefully considered in the care of the infant.

We feel it is essential that parent of severly defective newborns have the benefit of counseling as soon as the defect is discovered. This may be when the parents are still in the recovery room or it could be a few hours after delivery. The counseling may occur daily or several times a week and may continue for weeks or months, as long as it seems necessary. Klaus and Kennell discuss the need for this help in "Maternal & Infant Bonding."

> If parents of children born with multiple congenital defects do not receive help, they can have such lowered

> self-esteem that they totally withdraw interest in and concern for the child whom they perceive as a sign of their own badness. The results can be dramatic with total maternal deprivation or battered child syndrome as the outcome. (1977: 159)

Our job is to try to see that the infant has as healthy an environment to go home to as possible. While the outcome of most problems is not as dramatic as that cited above from Klaus and Kennell, if the parents have any feelings of guilt, anger or estrangement from one another, the child will not be getting the parenting and the kind of family life to which each child is basically entitled. We realize that, at times, helping parents to attain health is a monumental task. Some parents have come to us with severe problems of thier own as individuals and/or as a couple. While we recognize our limitations, we do not accept them as reasons for not giving some type of help to each and every parent. We believe that even the smallest influence in helping parents through the crisis of having a defective newborn is worth all the time and effort we can give.

We see the role of the counselor as a combination of counselor, teacher, friend and help-mate. As counselors we might guide a couple to look at certain problems or patterns in their relationship as well as helping them to express feelings which are just under the surface. We might also help them express and understand how certain relationships from the past affect their thinking and feeling during the present crisis. An example from our case studies illustrates this:

> A father who had a brother die in infancy was more fearful for his own child's life than reality called

> for. In another case a mother had a serious difficulty accepting a child with what we considered a minor defect. We helped this mother understand that she wanted a perfect child because her father had insisted that she be perfect and would not giver her his attention [love] unless she performed in a certain way.

Klaus and Kennell have also described parents who are affected by their past and the positive aspects of allowing this to surface and be dealt with. (1976)

As teachers we might give the parents the benefit of our experience with other parents, other babies like theirs, or our own personal experience as human beings. As friends we can listen and be there for them. We do not always have to have answers. We can love them. It is our experience hat parents want, need and appreciate time spent just being with them. Parents remember the attitudes of the staff people long after they remember the words that they used. (Klaus and Kennell 1976). As helpmates we might give them practical suggestions, phone numbers of agencies, or the name of a good baby back-carrier.

4.2 Implementation

As counselors we have done all these things. The parents are going through a crisis. We have the experience of being with other people who have had similar problems. Our experience makes it possible for us to help them. We do not have all the answers; sometimes there are no answers. We can even share that with them. "I just don't know the answer to that. As far as I know, no one knows," I might say to a medical question. Questions involving faith, ethics and morality are often unanswerable. The counselors can, however, tell them what other parents have done in similar situations and tell them what ethicists think and say about certain problems. When there are no answers and the questions have stopped, there is nothing to say. Being there for the parents is a big part of the job. We might sit for fifteen to twenty minutes without saying a word. One mother told me, "I didn't have anything to say but knowing that you were there for me was very important." Another mother said, "Everyone else is in such a hurry I can't even think of what questions I have. Now I have time and I don't feel rushed." A father said, "I've always felt that I'd better hurry and get it out, and that made me too uptight to think straight; having this time makes me feel cared about."

4.2.1. Implementation--Our Tasks

In order to send a child home to the best possible environment, we see our task with parents as three-fold:

1. To help parents feel what is happening to them. To help them talk about and ventilate their feelings of fear, anger, sadness and frustration.

For this we try to give them and environment which is conducive. A quiet, private place and an ample amount of time is provided. Parents are told that this is a time set aside just for them. We tell them that we have learned that many other parents have benefited from having a time to talk about what is going on with them, with their baby, or at home. Anything is fair to bring up during these sessions," they are told.

When it is appropriate we might tell them that letting their feelings show and talking about them is healthier than keeping them in. We feel that many times the role of counselor overlaps that of educator or teacher. A physician has always been expected to be a counselor, advisor in health matters. To do the healing work of counseling we must be teachers also. We might talk to parents about what happens if a person holds feelings in or withdraws. We might say something like:

> We know that this is a very difficult and stressful time for you. This is when you need each other the most. Some parents have a lot of difficulty with their relationship at a time like this, so we want to stress how important it is for you two to talk together and to share your feelings.

We often ask questions such as: "What are your feelings now? How do you feel about what I just said?" To ask about feelings is an important way to begin allowing parents to think in terms of their emotions. This is unusual for most hospital settings and it may take a while for parents to realize that, yes, we are indeed concerned about how they feel.

2. To help keep the relationship between the parents open.

We try to help them communicate through words and emotions; to share with the other person what is happening in their thoughts and feelings. As stated above, we might share with parents our knowledge of what has helped other parents. We might say how talking to each other and sharing feelings has helped other people in similar situations.

3. To help the immediate and the extended family deal with the crisis as well.

We are particularly concerned about the siblings and the grandparents because they are highly affected by what is happening to the parents and to the newborn. It has been our experience that most parents do not share their feelings and thoughts with their older children and that this causes problems for these children. One sibling began failing in school; another began wetting the bed; still another became terrified that she would get sick and have to go to the hospital herself. These problems diminished immediately when parents talked to the children about what was happening and, more importantly, began to share their feelings with them. "Mommy is very sad because the baby is very sick. That's why I'm crying," is one good approach.

We encourage parents to talk about the baby's illness or death as simply as possible and to use words that their children understand. Many parents thought they were protecting their children by not talking to them about the baby. Many considered the older child too young to understand. In these cases we explained to the parents that even though they did not discuss the problem openly or did not cry openly in front of the older child, the atmosphere had nevertheless changed around the house. The feelings of Mommy or Daddy could not be missed or denied. Children are very sensitive and they will readily sense a change and unspoken feelings. They know something is wrong even though parents are trying to put on a normal front. We explained that this protection is worse for the child than knowing the truth. The child feels something is wrong, but Mommy and Daddy are trying to say everything is fine. This is very confusing. In fact, this type of denial can make the best of us a little crazy.

Just as parents fantasize the worst before seeing a defective newborn, children have very vivid fantasies and fears, often worse than reality. A common problem arises because there has been ambivalence on their part, probably since they knew that a baby was expected. ("Oh, boy! A baby sister/brother." and, "I don't want a baby around here! Then I won't get as much attention!") Some children even wish there would be no baby or want it to go away or want to kill it.* Then when the real baby is sick, they may think they are to blame. They may become very frightened, ("If I wish something would happen, it will") or guilty ("I'm a bad person.")

Children need to be told when this happens that we all have good and bad thoughts and feelings and that this is all right. Of course children also need to know that just because they think a bad thought does not mean that their fantasy will come true. It can help if parents admit to some of their own bad feelings.

In many cases we have seen older children become terrified of becoming sick themselves or that Mommy, Daddy or another sibling will become sick. If the baby dies, children fear dying or fear that a family member might also die. Parents are urged to talk to their children about these fears on whatever level a child can understand.

Our experience has shown us that when parents are reluctant to talk to their older children, they themselves are still having difficulty accepting their baby's problems. Parents are still

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* Experience working with clients

uncomfortable with their own sadness when they cannot express it to their children. One mother said, "I just don't think I could talk to Debbie about her sister. I would just cry." We might say something like: "It's all right to cry in front of children. Tell Debbie that you are very sad about the baby, and that's why you are crying." Children need to know that parents cry, that it's OK to cry themselves. It is a normal, healthy way to be when someone is sad.

Another point we make is that when sadness is shared, it is somehow not as devastating. We usually discussed this in relation to the couple--mother and father--being able to give each other strength by actually crying togehter. It is very similar with a child. In fact, children are usually more open and can understand on a basic level which is not verbal but very pure and beautiful.

To summarize, we see our job, as parental counselors, as helping them understand themselves and their situation. We want to help them feel what is happening to them by talking to them and helping them ventilate feelings of fear, anger, sadness and frustration. We want to assist, if necessary, parents in their communication with each other at this stressful time. We also must help the immediate and the extended family deal with the crisis. Although each parent is different and each situation is different, there are five fundamental principles which we keep in mind when talking to parents.

4.2.2. Implemetation--Our Methods

We try always to talk to the parents together whenever possible; go slowly; give them time to integrate; use words the parents will understand; repeat what has been said several times; and ask them, "What did you hear?" I will now expand on these five methods.

1. Talk to parents together whenever possible.

It is potentially very harmful to talk to one parent at a time. Facts get garbled. One can never be sure if both parents are hearing the same information. We also like to have parents together so that we might observe how they relate to one another and see if they are able to give each other support. Sometimes one parent may shield the other from certain facts, believing that it is best to do that.

We realize that in certain circumstances one parent at a time must be spoken with. For example, if the mother is heavily sedated, or if an infant is transferred to our hospital while the mother has to stay at the hospital where she delivered, we are only able to talk to the father.

The following case is an example of what can happen when we only talk with one parent. Mr. and Mrs. C were highly educated people. Mrs. C was twenty-eight years old and Mr. C was thirty-four. They had one normal five year old daughter. The couple very much wanted a boy child, particularly Mr. C. This was to be their last baby. At birth, baby boy C was noted to have several "unusual" features. After the obstetrician finished sewing up the episiotomy he left the hospital. The pediatrician examined the baby and suspected Down's syndrome. Mrs. C was resting after her delivery and the pediatrician spoke to Mr. C outside the nursery, explaining the medical details. Mr. C told the doctor that he would break the news to his wife later.

Mr. C took a paternalistic role towards his wife. Men often do this because they feel they can and should protect their wives, shield them from hurt. This is a common occurrance. Occasionally we have seen the woman take on this "protecting" role. Rather than shield their husband from facts, women more often shield their husbands from their own emotional feelings about the crisis. They may know that showing deep emotions will make their man feel uncomfortable. Both types of pseudo protection are very harmful. If the man feels he is protecting his wife, it immediately puts them on an unequal basis. He has to shoulder the burden of the information and "act like a man", which in our society means not showing feelings, being strong. He decides when and what to tell his wife. Usually the medical facts are garbled by the time his wife hears them. On the other hand, if the woman holds back her feeling, it is harmful to her (personally, physically and emotionally), and to the relationship with her husband. A physician who is aware of these harmful consequences would never have allowed Mr. C to take on that burden. The doctor would have said, "Let's go down and talk with your wife. I think it's best that you both hear anything I have to tell you together."

2. Go slowly; give the parents time to feel and integrate.

Telling the parents too much too fast is a bombardment of verbal stimuli which will not get processed. If we had a lot of information to give parents or if there was a considerable amount of material coming from the parents that needed processing, we found it more helpful to have them come in for another session. This was preferable to trying to cram in too much information at one time.

3. Use words that the parents will understand.

This sounds obvious. However, we have heard physicians trying to explain a problem to a parent in language that only a physician would understand. Walker, Thomas and Russell write that doctors tend to use technical landguage and that parents do not always understand. "Professional jargon tended to be used in explanation and even when the anatomical deficit was acknowledged, its functional complications were not." (1971) It is easy for a doctor under stress to assume the medical role and status and use it to stay safely apart from the personal crisis. In addition, some physicians simply need more experience talking to parents.

4. Repeat what you have said several times if necessary.

Parents who are in an intense emotional situation do not always hear or understand what is being said the first time around. Even if ample time is given and a simple explanation is used, parents are often unable to assimilate the medical facts due to the emotional climate. We know that during the stage of shock, parents become numb and withdrawn. At this time it is a difficult task to get through to them with medical information.

Also, during the denial stage what we tell them is often denied. Parents are not ready to accept or believe what we are saying. Often parents literally do not remember hearing words which were just uttered. This is one reason we always ask parents what they hear and understand during each session. Klaus and Kennell tell us:

> ...a physician who knows about the disorganization which parents experience during the stages of shock and denial will realize that information about the child's condition and progress may have to be repeated several times. (1976:177)

This does not mean that information should not be given early. It means that we do need to be aware that parents' understanding of the situation will probably be slow. We should tell the parents of their child's anomaly as soon as possible. At that time we should give them an overall view, a simple explanation and add that we will be back to discuss any questions that might arise. Giving the parents a few hours may be all they need to formulate questions and hear more information. Parents should know the facts right away, including what is not yet known, what is suspected, and what procedures will be taken to discover the unknowns.

A mother has stated, "Honesty and repeated discussion are essential; everything that could go wrong should be told immediately." (Walker, Thomas & Russell, 1971: 466). Parents tell us that it is important for them to know the truth right away. One mother was annoyed because a nurse made light of her child's problem by saying: Oh, it's nothing to worry about. You just relax." In this case the problem that was "nothing to worry about" was spina bifida. Certainly this mother had something to worry about and is probably worrying about her child to this day.

5. Ask them: "What did you hear?" Find out what they understood.

As mentioned in the previous point, we should aways check with parents to find out what they heard and understood. This is done at the end of each session. With parents who are having particular difficulty in understanding, hearing or accepting, we might ask them over and over again, "What do you understand about what we just told you?" or "What did you hear?" In this way we know where we stand with them and, therefore, we know what work we must do to help. We must check to see what their blind spots are. If they are not hearing certain things, there is a reason. We can then go about helping them explore that reason.

Be sure to ask both parents individually what they understand. It is a mistake to work with a couple and allow one to be the spokesperson. What one person says does not necessarily reflect what the other person would say. One parent may be in a very different place emotionally than the other. For example, one many be in the denial stage and the other dealing with anger. It is important for us to know where each individual is in order to help them understand each other better.

4.3. Problems Inherent in Personalities Of Parents

When parents are going through a crisis, any problems with an individual or with their relationship will bare their ugly heads. This can complicate the job of helping them with the current crisis of the newborn. People are complex. Each parent can bring an infinite combination of details into this moment. If a person has problems related to his own growing up, for example, a difficult relationship to his own parent or parents, or an unfulfilled childhood need, it will affect his ability to cope with the current crisis. Although a thorough discussion of all such possibilities is not within the scope of this monograph, the counselor must be prepared to help parents work through old problems that become apparent during the sessions.

Klaus and Kennell (1976) tell of a mother who mourned her premature newborn, sure that she was going to die. It turned out that her infant sister had died when this person was five years old. Her mother had blamed the doctors for killing the baby by operating. This left the woman with a fear and mistrust of doctors. At the birth of her own child, when the nurse took her infant from her, she relived the scene of her sister's death. Later, with the help of her doctor, she was able to understand and began to accept her own daughter without the old fears hanging over her. In our experience, we have found that when parents had a previous child die, they were terrified that this child would die also. (See chapter 8.3.)

Examples of a lack of mothering during childhood often become apparent during a crisis with a newborn. New mothers and fathers with defective children are under tremendous strain. They need a lot of support and love in order to give love to their child. (It is somewhat like a bank account. Put in X amount of dollars, withdraw X amount. The amount we can withdraw is never more than what we had banked in the first place. This same is true of love.

A person cannot keep giving and giving after the reserves are gone.) If the amount of good feeling and love is low to begin with, perhaps because of needs unmet in childhood, the amount that can be drawn upon is limited. Dana Raphael spoke about the need for mothers to have mothering. Raphael named the person who gave "mothering help" when the woman's own mother was not available, a dula.*

We have found that mothers often want their own mothers to support them with their newborn. On the one hand, if they are lacking past and present maternal support, they sometimes become aware of old feelings and longing or anger toward their own mothers. Another response is wanting to go home to mother. One woman who was trying to cope with the illness of her premature twins told us on several different occasions: "I just want to forget all of this and go home to see my mother," and "His mother is coming down to help us, but it's not the same. I want my mother here." (For a similar case, see chapter 8.1.3.)

We have also found that parents react in similar ways to how their parents had treated them. One father began fiercely yelling at his four year old for no apparent reason. We discovered that his own father had been very harsh with him. Our client reverted to his father's behavior at times of great stress. He told us, "I realized that I have been very angry at my father for treating me that way, but rather than deal with it, I just started yelling at Bobby." Our client was able to reexperience his old feelings about his father and then extract these old emotions from the current feelings he had for his son. This man reported that

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* Dana Raphael, Ph.D., Public Lecture, 1973, NYC

he went home and cried with his son, told him he was sorry for yelling at him and explained about the baby's illness and the stress that it produced. "Bobby gave me a hug and said, 'That's OK, Daddy.' That really made me sad and happy also. I don't want to treat him like my father treated me."

4.4. Problems in the Relationship Between Parents

If parents have trouble communicating with each other in normal day to day life, they usually do not start communicating during a crisis without help. If one person is dominant or active and the other passive, they will of course bring that into their sessions. If the woman acts like a mother to her husband or the man acts like a father to his wife, we will see it clearly. Further, we have worked with parents who "out of the blue" start talking about their sexual incompatibilities or parents who suddenly bring up old anger--"That reminds me that for the last five years you have forgotten my birthday!" Whoever they are, they bring their uniqueness into the counselor's office, and we must meet them there.

We do see parents who handle the crisis beautifully and seem to gain strength in their relationship. These are the parents who came to us as fairly mature individuals with a stable relationship. Still, these parents benefit from our sessions as well as those who have more serious problems and who require more time and effort.

With all parents, our first goal is to get them talking with each other in our office. We begin by speaking about their feelings and giving them an opportunity to being to relate and open up.

We use questions like:

1. How do you feel right now?
2. How do you feel about what I just said?
3. How do you feel about what she or he just said?
4. Have you told him or her that?
5. Tell him or her that now.
6. What do you want from her or him that you aren't getting?

A relaxed environment with someone who is genuinely interested is usually enough to begin the process of opening up. Parents in a crisis situation are flooded with feelings and the feelings are often bursting to get out.

Of course, parents are more difficult to help if they are very afraid or have been taught to hold back their feelings. We have found that these people often benefit most from having sessions to explore their feelings and to share, perhaps for the first time, some of these feelings with their mate. For example, we were working with the parents of a very small, very sick, premature infant, whom I will call Mr. and Mrs. Andrews. Mr. Andrews was a well-educated, highly successful businessman. He was tightly in control of himself at all times. Mrs. Andrews was a registered nurse. She was more aware of her feelings that her husband. However, it was clear that he set the stage for what was to be said, done, or even thought in the family.

During our second session we were talking about guilt feelings that either might have in producing their child too early. After several minutes, Mrs. Andrews suddenly began to cry. After a long while she said, "I have to tell you something. (long pause)

I have never told anyone before. (long pause and crying) I'm so ashamed!" (long pause, more crying)

We sat with Mrs. Andrews for about half an hour before she could finally tell her husband what she felt so guilty about. She had masturbated and she connected this with the premature birth. As the session progressed she also told us and her husband that she was very frustrated with her sex life and her life with him; that he was cold and never there for her; that he only wanted sex with her every five or six weeks. Complicating all of this were her old fears and strict religious upbringing relating to sex. She had been taught to believe that sex was dirty and evil outside the marriage bed, and that included masturbation. The doctor assured her that masturbation had not brought about the premature birth of her daughter.

We met with these parents two to three times a week for the next six weeks, partly because of their strained relationship and partly because their daughter was very ill. (As is typical with very small premature infants, she had a lot of serious ups and downs.) After Mrs. Andrews had ventilated the initial outburst of feeling, she stated her doubts that the marriage would or should continue. With Mr. Andrews' cooperation we began to help them communicate. We slowly got to the heart of some of the basic problems in their relationship. We suggested that they set aside one hour a day to talk with each other. That the hour was sacred and could not be put aside for any other reason. We also worked with Mr. Andrews about his inability to show feelings. We gave them opportunities to express feelings and to literally begin to touch each other. Slowly their communication increased and became more effective. Their daughter grew and got better. After three months they were able to take her home. We recommended further marriage counseling after their termination with us.

These are the types of additional problems that any neonatal counselor will encounter when working with parents. These human problems cannot be overlooked or "shoved under the rug" if we are to be as effective as possible in helping parents and their defective newborns.

CHAPTER 5

WHAT ABOUT GOD? -- HOW RELIGIOUS QUESTIONS INTERACT WITH THE COUNSELING PROCESS

5.1 Introduction

> For everything there is a season, and a time for every
>   purpose under heaven:
>
> A time to be born, and a time to die;...
>
> A time to kill, and a time to heal;...
>
> A time of love, and a time of hate;...
>
> (Ecclesiates 3:1-8)

We have found that all parents of defective newborn children ask the same basic questions--what kind of a world is this, ANYWAY? Am I being punished? Who is responsible? I'm angry and I don't know who it's safe to be angry at. These relate to our deep needs for ultimate explanations, especially explanations of what is Good and what is Bad. Parents who are aethists might address these issues in very secular, philosophical or psychological terms. Others may address them in liberal religious terms and still others in very fundamental, conservative terms. The range is wide, but the questions are the same. While the counselor cannot believe in the particular religious or irreligious orientation of all clients, the counselor must help them express themselves in the language and concepts to which they are accustomed. Most of our clients and we, ourselves, come from the Judeo-Christian background. Therefore, the experience we present in the following sections was within that tradition. Counselors from other traditions or working with parents from other traditions will need to adapt our work to their own situations of ultimate Good-Bad, Life-Death.

5.2 Fate and Fear

In almost each experience that we had with parents, the concept of God and religions had a powerful effect. After seeing this at work we began to bring it up in sessions. If parents did not talk about it themselves, we might ask: "Are you religious people?" or "Do you consider yourselves religious?" This question would usually open the subject so that we could explore their thoughts and feelings about God in relation to their present situation with a sick or defective newborn.

> A mother of twins, "God knew that I didn't even want one baby, so He sent me two!"
>
> A father: "I'm really angry and there's no one to be angry at. I just can't get angry at God!"
>
> A mother: "My minister told me that God may have sent me this sick child because I'm a sinner. I smoke and in our church that's a sin."

Like the minister who suggested that the mother was being punished for something she did, other professionals may similarly influence parents. I was talking with the head nurse of a small hospital about what might be done to emotionally support a mother whose baby was very ill. I asked her what she would say in a situation like that.

> Nurse: The main thing I end up saying is that it's really too bad that it had to happen, but I always feel that no matter what happened it's God's will. If it weren't meant to be, it wouldn't have happened.

Pam: You tell them that?

Nurse: Yes. (long, long pause)

Pam: Why do you think God would send someone a sick child?

Nurse: I think God has different ways of trying to get through to people. I don't believe that God gives anybody more than what they can handle; then again you know, I think at the time it's probably hard to understand why, but there is always a meaning, a reason for doing it.

Pam: What is their reaction to your telling them that? (long pause) Do you remember anyone's reaction? (long pause) Do you feel it helps them to say that?

Nurse: I think it's important to know how religious they are (pause); if they believe in God, they accept God as the creator. The one who has power to do anything and everything. I think it's individual if they really believe. I've never seen anyone so upset that they were ugly with what was being said to them. I've never seen anyone ugly or belligerent or really regress.

This nurse has her own belief that God sends problems for some reason. She may be pushing her own belief on to the parents of very sick newborns. This leaves no room for airing the feelings which virtually always come up on such cases.

Fear of God plays an important role for many of us. If parents are angry, they may be punished, go to Hell (whatever their concept of Hell may be). If, on the other hand, parents doubt the existence of God, the crisis of a defective newborn may make them especially fearful and insecure because they are doubting an after life for their sick child, and ultimately for themselves. We have found that fears are often linked with anger--anger at God.

In the previous example, feelings of anger at God would be hard to express if someone were standing there telling you that God sent you the problem in the first place, and it was for your own good. This could lead to unresolved guilt--Mom is angry at God--it is too scary to express that--and she feels guilty for feeling angry at God. God is supposed to be all powerful and all loving. How can a loving God send you a deformed or seriously ill baby? Most people we have worked with have felt frustration and anger which focuses on God. Many are afraid to express that anger, some because they would be afraid God would be offended, maybe even take revenge. They already have a defective child. More revenge might be more than they could stand.

5.3 Anger

Traditional teaching tells us that it is blasphemous to be angry at God. This makes it very difficult for some of us to allow the anger we do feel to surface. Of course there is anger and frustration when an unexplainable disaster confronts us, such as a defective or sick newborn, or the early death of a loved one. Typical religious funeral services in America tend to deny the death and glorify the promise that the dead person is now with God in a better, happier existence. What of a baby dying before having a chance to live, or a young mother plucked from her family in the prime of life? Don't we have a right to be angry about these things? Yes, we do, and we are! We believe that the problem is giving ourselves permission to be angry.

The Reverend Patricia McHenry said:

> When my mother died, I was 13. I focused on the beauty of it. I said things like, "She is now with God. God wanted her to be with Him. She is in a better place." Only years later did the emotional pain hit me. When I finally accepted the reality that my Mother was dead, I felt betrayed. How could God do that to me?*

It is not unusual for parents to feel betrayed and forsaken at the birth of a sick or defective infant--especially if their infant dies. Parents cry, wail, moan and ask why. They question themselves, their faith and their God. What have I done to deserve this? Is there really a God who can be this cruel? Help me, God! Why aren't you helping me, God?

There are many Biblical references to these feelings of betrayal or of being forsaken. In The Psalms, David says:

> My God, my God, why has thou forsaken me?
> Why art thos so far from helping me,
> from the words of my groaning?
> Oh my God, I cry by day, but thou dost not answer;
> and by night, but find no rest.
>
> (Psalms 22: 1 and 2)

These words could have been echoed by each parent we have worked with who had a very sick or defective newborn--if they could give themselves permission.

In the long run, I believe that feeling abandoned by God may give us a chance to deal with God directly and on a more physical level. This may help us feel closer to God and give us a chance to find God within ourselves. Accordingly, when working with parents, we try to encourage them to express their feelings about God to us or to talk to God directly. It is our experience

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* Personal interview

that parents feel much better when these feelings are surfaced and expressed. We have told people to go ahead and be angry at God. God is strong enough to take it!

My concept of Jesus is that he was a strong and passionate man. There are many Biblical references to his becoming angry. Probably the one which is best known is when he drove the money changers out of the temple:

> Jesus entered the temple precincts and drove out all those engaged there in buying and selling. He over turned the money changers' temples, and stalls of the dove sellers, saying to them, "Scripture has it; My house shall be called a house of prayer, but you are turning it into a den of thieves."
>
> (Matthew 21: 12 - 13)

Concerning anger, the Bible tells us:

> If you are angry, let it be without sin. The sun must not go down on your wrath; do not give the devil a chance to work on you.
>
> (Ephesians 4: 26 - 27)

and:

> Get rid of all bitterness, all passion and anger, harsh words, slander and malice of every kind.
>
> (Ephesians 4: 31)

5.4 A Time of Hate...A Time of Love

What we are not told is how to go about getting rid of all that anger and passion; how not to let the sun go down on our wrath. Modern psychiatry does offer some help. In Bioenergetic Therapy people are encouraged to yell, hit, kick and cry. The body and mind are treated as a unit and expression of feeling is encouraged, to include the body as well as the mind and voice. If a person is very angry, he might be encouraged to hit the bed or wring a towel while yelling, "I'm mad!" or "I hate you!" or whatever is appropriate. "I felt total anger," said the father. "Just anger. I was really mad at God, I guess. Why us?" (Cohen 1973; 10) When working with parents we are sometimes limited by hospital space or convention. We can, however, encourage them to express their feelings and we often suggested that they go home and hit the bed and yell at God.

People feel better after they have fully expressed a strong feeling which have have been harboring. It clears the air, gets it off their chest. Allowing the negative feelings to be expressed makes room for more positive feelings to emerge. An example of this is when we are very angry at someone we love. So angry that the love seems to be lost and all we can think of is the anger. After it is expressed, the love returns. The point of anger does not seem important. We might even forget just what it was we were angry about. A father said: "I was realy afraid to yell at God, but once I did, I felt a great burden lift from me."*

A mother told me: "I was afraid I'd be struck by lightening or something when I told God how angry I was. As I did it and especially afterwards, I knew it was OK with God that I was angry."*

We usually feel better and more loving after the negative feelings are expressed. A priest, the Reverend Dr. Betty Rosen-

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* Personal interviews with parents

berg, said: "I was taught in confirmation class the mechanics of taking communion. The wafer symbolized Christ or really was Christ. You were supposed to have this attitude of reverence. I got the idea that I wasn't supposed to chew it, just let it melt on my tongue.

"One day a few years later, I was kneeling at the altar rail and received the wafer and put it in my mouth and bit down on it with anger. I knew I was really angry and I knew it was OK to be angry, even though that was definitely not what I was taught. I felt that I was doing it [being angry] with God's full approval. That is the first time I can remember being angry at God. That really changed my whole relationship with God. With peers and family there were things that were unacceptable, like anger. But I knew that <u>all</u> of me was acceptable to God. In fact, I felt encouraged by God to express my anger! It was like reaching a whole new level of communication. I was really moving out of being that submissive little girl into being an adult who could talk equally with God. From then on I would always tell God when I didn't like things and when I was angry. After than I felt much closer to God."*

We encourage parents to talk about their feelings regarding God and religion. Sometimes we suggest that they talk to their minister or priest or we might suggest one for them to talk to if they do not know someone themselves. We feel that because these feelings are so universal we can not ignore them. We must help

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* Personal interview

parents with these difficult feelings as well as any other feelings they have. We must not push our own feelings of guilt or fear on parents and we must guard against other members of the staff doing so.

CHAPTER 6

COUNSELING PARENTS IN LIFE AND DEATH DECISION MAKING

6.1 Introduction

Parents confronted with the agony of making a decision regarding the life and death of their infant have to deal with religious, moral and ethical issues.

A baby who was born to parents who had planned and anticipated the first was found to have almost no functioning brain. The parents received counseling. They were told that in the opinion of the neotatologist, further life prolonging measures would only prolong the infant's suffering. He advocated the discontinuation of support care, thereby allowing the infant to die. The parents decided this was what they wanted. They told the physician to discontinue extraordinary care. The infant died eight days later.

Approximately fifty sets of parents must make decisions such as this one each year in our hospital alone. More physicians everywhere are asking parents to help in the life and death decision making for these severely ill or defective newborn. The following examples are reported by Duff and Campbell in their important paper, "Moral and Ethical Dilemmans in the Special Care Nursery:"

> An infant with Downs Syndrome and intestinal stresia, like the much publicized one at Johns Hopkins Hospital, was not treated because his parents thought that surgery was wrong for their baby and themselves. He died seven

> days after birth. Another child had chronic pulmonary disease; by five months of age he still required 40% oxygen to survive, and even then, he was chronically dyspneic and cyanotic [breathed with difficulty and showed blueness of skin, as from imperfectly oxygenated blood]. The nurses, parents and physicians considered it cruel to continue, and yet difficult to stop. All were attached to this child, whose life they had tried so hard to make worthwhile. The family had endured high expenses (the hospital bill exceeding $15,000), and the strains of the illness were believed to be threatening the marriage bonds and to be causing sibling behavioral disturbances. Oxygen supplementation was stopped and the child died in about three hours.
> (Duff and Campbell, 1973: 891)

> When maximum treatment was viewed as unacceptable by families and physicians in our unit, there was a growing tendency to seek death as a management option, to avoid that cruel choice of gradual, often slow, but progressive deterioration of the child, who was under these circumstances in effect made to kill himself.
> (Duff and Campbell, 1973: 893)

Exploring the ethical and moral literature is not within the scope of this paper. I have, however, introduced these questions in chapter 1. In addition, there is considerable information available to the interested reader (e.g., Who Shall Live? by Leonard J. Weber).

From our experience, we believe that parents and physicians have a right to choose the treatment of the severely damaged infant. Our position in the treatment of infants and their families is one of ethical tolerance. There are many different feelings and positions about the care of the defective newborn. We acknowledge, and in most cases support, these differences. Parents are different. Families are different. What is right for one family or one set of parents may not be right for another. It is essential that each baby and each parent be treated as an entirely unique individual.

We also acknowledge that there are not always right and wrong answers to these difficult questions. As with many things in life, there may be simply choices. We try to help parents make the best choice that is possible for them at any given moments. We try to help them make the best human decisions possible; that is all we can ever do. Sometimes circumstances change; then our decision would change also. We are never firmly wedded to a decision. We also realize that it often is impossible to change a decision at a later date.

The following is an excerpt from our case studies in which the parents <u>were able</u> to reverse a decision. A baby girl was born with Down's syndrome and duodenal stenosis. The medical situation was very much like the well publicized Johns Hopkins case. In the Hopkins case, however, the decision was made and the baby was left entirely to the medical staff. The parents were not part of the care taking of their dying baby. In our case the parents initially decided not to treat their child. When they thought their infant was suffering because she was not dying quickly, they reversed their decision and decided the have the operation.

> June 8, 1976 - Judy tells us, "I cry a lot and spend time in Susie's room. (Pause) I have a picture taken in the hospital. I look at this picture and ask Susie, 'What would <u>you</u> have me do? What choice would <u>you</u> make for yourself?' Of course she can't answer me, so I have to make the decision for her. (Pause) I think a little suffering is better than years of suffering."

June 10, 1976 - Parents have come in every evening to sit and hold Susie. Susie is losing weight slowly. Judy and Don reconfirmed their decision not to operate. We talk mainly about their feelings as Susie worsened. I asked them to think about her getting worse and dying. Judy said, "I don't know how I'll feel. I'll have to take it as it comes."

June 12, 1976 - They reiterated time and time again that their first decision was and is the right one. In talking about the possible rethinking of the decision, Judy and Don understood that we may have to rethink our decision if Susie does not do "poorly enough."

June 14, 1976 - Judy and I have been having second thoughts on the operation. Judy said to me as I left this morning, "I think I want to have the operation. This is taking too long." We're rethinking our decision. Dr. X (the surgeon) did not think that we had to rethink the decision until next mid-week. "We should all sit down again to talk before any new decision is made," I said. "The neonatologist told Don, Susie is comfortable and in no pain. Perhaps that will make Judy feel better. We can sit down and talk again on Monday."

June 16, 1976 - Medical: Susie has gained very slightly. Session: Judy immediately started talking about their change of decision. Bob also agreed. They explained that they could not stand to prolong Susie's suffering any further. I ask them to share with us the process of changing the decision, since the Friday they had talked with us. Judy said, "It was Sunday before I decided for sure. (Pause) Susie forced our hand," she explained. Don stated that he thought their original decision was still best, "But if Susie lingers on, I could not live with myself. (Pause) It would be too hard on us."

I then begin a new approach. I asked them how this new decision would change their lives. First Don answered, "Time; money; job; staying in this area; difficulties of daily living."

I told them I now wanted to play devil's advocate. I asked, "How will you feel about this decision when Susie is 15? (Pause) Looking back on it."

> Don answered, "I don't know, but it's the only one I can make." Judy agreed.

These parents changed their decision based on the degree of suffering they imagined Susie to be going through. Parents must know that, once they make a decision, the situation may change and so might their idea of what is right.

With these awesome decisions to be made more and more often in modern medicine, how can nurses, physicians, clergy and counselors help parents? Helping parents in life and death decision making is very difficult for most of us because we are still struggling to find the answers to these problems for ourselves. Duff and Campbell tell us: "Repeated participation in these troubling events did not appear to reduce the worry of the staff about the awesome nature of the decisions." (1973:891)

Because we believe that physicians and other staff people can make a difference in the lives of these parents, we instituted our counseling process. By using some basic information and guidelines, we can help parents make these decisions and can even touch parents with a positive force in so doing.

> Some [parents] claim that their profoundly moving experience [in decision making] has provided a deeper meaning in life and from this they believe that they have become more effective people. (Duff and Campbell, 1973: 891)

In summary, we try to provide the parents with time, effort, emotional support and caring. We give them a safe place in which to work through their thoughts and fears. They need a place where they can talk and ventilate fear, anger and sadness, as we have previously discussed. Also they need help with their marriage relationships, particularly in communicating under stress and in sharing their feelings with one another.

In Chapter 4 we presented the need to help the immediate and extended family cope with the whole spectrum of what is happening in their lives. We are concerned particularly with the other children and grandparents. Although they are sometimes reluctant to share the pain they are experiencing, parents can usually find needed emotional support from their families, even their young children. The following example comes from our studies:

> Mr. and Mrs. George's baby was slowly dying. They decided that they would take their daughter home and give her as much love as possible until her death. The Georges had a sixteen year old daughter and a four year old son. Both children came to our office for several sessions and were part of the decision to take the baby home. They were also brought into each part of the emotional issues as they arose. The baby died after three months. The whole family felt that there was learning and beauty as well as agony in their shared experience.

We further feel that it is our job to help the parents bring their thoughts and feelings together for their final decision. Parents need to explore their "gut" feelings as well as their intellectual thoughts and come to the mid point which is their reality. Only then can they make their decision honestly and fully. We will discuss this process more after we have explored who makes the decision about the care of the defective newborn.

6.2 Who Decides?

While the initial decision is made by the physician, we feel very strongly that the ultimate decision about the care of a baby must be made by the parents. Doctors and staff people must give honest, generous and clear input to the parents, including their own recommendations, so that the parents have sound information on which to base their decision. The baby's physician needs to make a thorough evaluation of the medical facts and also search his own soul for what he thinks and feels is best, before presenting the situation to the parents. The presentation must include all angles possible, for example:

> A. If we treat the baby vigorously he may live, but only in an infantile state for months, maybe years. He will be difficult to care for and you may have to institutionalize him. It will be quite expensive. Your family may suffer. You will have to live with this decision and its moral and ethical implications.
>
> B. If we do not treat the baby with any extraordinary means, we expect that he will die shortly. We cannot give you an exact time. You will have to deal with this decision as well, and explore its moral and ethical implications. In our experience, this is what we think the truth is. We recommend discontinuing support care. We can make mistakes. We are not God, however; this is the best human judgment we can make. The final decision is yours.

Unless we tell the parents all possibilities of the care we are suggesting, be it to treat vigorously or not to treat at all, we cannot obtain truly Informed Consent. The law states that parents must be informed in order to consent to a procedure. Being informed means that they must fully understand, to the best of their ability, all considerations of the type of care we are suggesting. "A neonatologist says: 'Parents have the right to know everything, at every step. You should never act until you have truly informed consent from the parents.'" (Cohen 1964: 10)

To summarize, we believe that when parents are asked to make a decision about the life or death of their child, they should understand all aspects of the different possibilities of treatment. We feel that it is our duty to help them explore all questions leading to their conclusion, to stick with them through their resolve, and give them follow up care after they have left the hospital.

6.3 The Physician's Rule

In a personal interview, Dr. Raymond Duff discussed how parents would be approached and how an initial evaluation would be made:

> The people concerned with the care of the child ought to put together an honest assessment of what they're facing. If the doctors and nurses think it's a pretty bleak picture, then this is what they ought to say about it. Sometimes they're mistaken but ought to say so. They must outline what the medical options might be; also what the moral options might be, as have been presented in situations like this in the past. Medical options are not always clear. Moral options are not always clear.

Another physician has said:

> Doctors make the recommendation often after consulting with doctors and nurses from the most junior to the most senior. Also after talking to the parents, the doctor must make the medical recommendation. (Aver et al, 1973: 278)

Physicians certainly must make their recommendations to the parents. However, in order to get truly Informed Consent, they must also talk to parents on a human level. They cannot give their recommendation and then retreat. Physicians must be willing to discuss their ideas and questions and be able to tell the parents the whys and wherefores of their decision as well. This includes their human judgment as well as their official medical judgment. Parents might want to know, "What would you do if this were your child?" The physician ought to be able to tell them honestly. A neonatologist reported:

> "I've never made a professional decision I wouldn't make with my own child." He continued explaining that what he said is often an agonizing process. The final question I ask is, "What would I do if this was my own kid?" (Cohen, 1974: 10)

Physicians have several options when faced with a life or death decision. Dr. Judson Randolf tells us that a surgeon, for example, might take one of the following positions:

1. I am a physician, not a philosopher; I will go ahead and operate.
2. I will not operate; if you want an operation; you will have to get yourself another physician.
3. You are the parents; you decide.
4. I want to help you understand all aspects of the case. I will give you my recommendation, then you will decide.

Dr. Randolf considers the first two possibilities "cop-outs." The fourth possibility is the only one which offers the parents the ability to give their informed consent. In this case the physician must, to a degree, become the parents' counselor. (Avery et al, 1973)

Dr. Randolf continues:

> The physician has to cross that line of objectivity and passive role as a counselor to the family. I believe that only if he crosses that line can he then let the family be fully informed, and if they wish, come back to a role of, "Yes, we do understand this and appreciate your willingness to serve us and to make our baby comfortable and to take the burden off us of a long-standing life as you have explained." (Avery et al, 1973: 269)

The decision for the physician is sometimes relatively simple and can be made in a matter of moments. An infant born with anacephaly, for example, would present an easy choice for most physicians. Other more complex or grey examples, such as the case that Drs. Duff and Campbell describe, of the five month old respirator "addict," might take weeks of agonizing over. Physicians go through a difficult process each time they must make a recommendation. They might ask themselves questions such as these: "Can it be self-aware? Or will it have no aspects of human personality?" (Cohen, 1974: 10) These are qualities which many physicians believe make a baby capable of giving and receiving love, in essence of being human. (See also the ethical discussion in chapter 1.4.3.)

Another physician tells us: "My basic value is, if I believe the infant is going to be able to give and receive love, we ought to make every attempt to save the baby's life." (Cohen, 1974: 10). In some cases of severe handicap or defect, families and physicians weigh the degree of suffering against the value of life and decide that death would be better than prolonged suffering. We feel that there are times when it is better not to extend life. For example, parents have told us, "We love our baby so much that we cannot permit him to live a life full of suffering."

A father told us: "We read about the long-term effects of this problem, about what a child of twenty or twenty-five would be like. This helped us make our decision. We don't want our baby to suffer."

In our work with parents, they often weighed short-term suffering and came to the conclusion that short-time suffering was the better choice. A mother told us, "I love Billy more than anything. I have to do what's best for him."

Parents additionally weighed their own suffering and that of the other children in their family. Sometimes they decide that their own suffering was an important consideration in their decision making. For example, Duff and Campbell write:

> Living with the handicapped is clearly a family affair, and families of deformed infants thought there were limits to what they could bear or should be expected to bear. (1973: 893)

Once the physician makes a decision, he will then go to the parents. In a newspaper interview for the Washington Post, Dr. David Abramson said that once he knows that what he wants for the child is "no treatment," he tells the parents that is what he recommends as the treatment of choice. He added:

> I don't ask them [if the treatment should be stopped]. I tell them. They have known all along where I was. I tell them my feelings have changed; I think it's time to stop treatment. Ninety-nine percent of the time I know what their reaction will be. But my decision is what I want to do. What I do is what the family tells me. (Cohen 1974: 10)

A physician should not be in the position of being the only person that gives parents input at this time. Although parents need sound medical advice, the decision is ethical and personal as well as medical. We urge parents to talk to their own clergy or seek ethical input from outside as well as consulting with their families. We have suggested a counselor or clergy-person if the parents did not have one of their own. This is particularly important for parents if their own physician can not or does not take the time to counsel them. Weber summarizes:

> The physician, though he has a very important part to play, should ordinarily not be the one to make the actual decision. Such a decision is an ethical decision, not precisely a medical one. While it can only be made wisely when there is sound medical information, the decision itself is largely one of values. We should not ask physicians to make moral decisions for others. (1976: 105)

In conclusion, we believe that parents must make the final decision about their own child. They need the help and input from the medical experts (physicians, nurses, neonatal counselors) and clergy and ethicists, as well as from their families and society.

6.4. The Counseling Process

The counseling process with these parents is often very time consuming. It begins as soon as the defective child is born and does not end until months after the child is at home or has died. When parents are contemplating a decision during the counseling process, we must be sure that the process itself is a healthy one. We try to be sure that during that process, the parents are communicating and that neither parent is acting out terribly neurotic characteristics. Our job is to help them explore every facet of their decision and the decision making process, so that one year or ten years from now they will still be able to live with the outcome.

Therefore, it is not enough to have the decision itself. We have to know the whys and the wherefores of the process. Otherwise there may be terrible repercussions at a later time. Our data have two examples of poor decision making processes and the negative effects.

1. The father [husband] is boss. He's making the decision. The wife dutifully goes along and mouths his words. A week later she goes into a deep depression. She has not been true to herself. She is harboring anger toward her husband. Her whole family suffers.

2. Both parents have conflicted feelings about the decision. Their intellectual one is that the baby be allowed to die. They take into account the financial considerations. Their religious one is that they have to keep going at all costs. They are confused. They decide to continue. Later they are faced with astronomical bills because their child must live in an institution. The father refuses to go to church any more. After a few years, their marriage disintegrates.

L.J. Weber writes:

> Parents should be able to know their own reasons and explain them to their own satisfaction. It is only when reasons for and against a certain procedure have been wrestled with that one can be really sure he has decided carefully. People disagree on what is morally right and to some extent, it is true to say that what is moral is a matter of opinion, but that does not mean that such an important decision as whether a deformed child should be treated should be an unfounded opinion, made a certain way simply because the parents "feel" that it would be best. Recognizing the reasons protects somewhat against arbitrariness and ensures some attention to the issues at stake. (1976:115)

Therefore, in our practice, we ask parents to talk about and defend their reasoning as a protection to the infant, but more perhaps as a protection to themselves. If parents do not do considerable individual soul searching and communicating with each other, what was perhaps not thought of, or was perhaps repressed, might cause problems later in their lives. Therefore, one goal of our sessions is to help parents bring out their thoughts and their feelings--even the frightening and "unmentionable" thoughts and feelings. In our experience what is frightening and "unmentionable" is, in fact, the most important thing to work with during a counseling session.

The worst dilemma for parents is when thoughts say one thing and feelings say another. As in the example of the parents whose feelings accepted their religious teachings (saying, "Go ahead at all costs,") and their intellect said the opposite ("We must stop,"), many experience internal conflict. This conflict and confusion make a good decision impossible, unless the parents can explore all aspects of the situation. We must give them time and guidance during this period of intense need to go through the process of "muddling through," as Dr. Raymond Duff calls it.

In a newspaper interview, Dr. David Abramson was asked, "What happens if you make the wrong decision?"

> All that I am required to do, all that I can do, is make the best decision I can given the information. Can we be wrong about the condition of a baby? Absolutely. But you're not God. You can't play God. You're a human being with human frailties, you just have to make the best decision you can. I don't have an obligation to be right all the time, but I have a severe obligation to make the best decision. Some of the assumptions may be wrong, and I always present that [possibility] to the parents. But one alternative isn't right and one isn't wrong. They are both alternatives. (Cohen, 1974: 10)

In my experience, Dr. Abramson has an unusual understanding about the depth and intensity of the problems parents face. It was not unusual for him to share his thoughts and feelings with the parents that he counseled. Experiencing this feeling of humanity about his part in the process helped parents to understand their own humanity in decision making. We are, after all, asking them to trust their humanness, even to the point of making human error.

Once the parents have made their decision and have gone through the process thoroughly and have explained their reasons for that decision, we have one further choice. We turn around and play out the other side of the decision, or we might ask them to play their own "Devil's Advocate." One example of this is in the first section of this chapter, under the date "July 16, 1976." We often do more role playing, such as:

> <u>Counselor</u>: OK, we know that there are two sides to this decision. The side you are telling me now and the opposite position. What does that opposite, let's call it the negative, have to say to you now? Let's have the negative side sit in this chair and the positive side sit here.
>
> <u>Father</u>: (the opposite side): If you operate, you'll have to stay in a job you hate, spend a lot of dollars and be really tied down. You will probably have to institutionalize him later. You'll suffer.
>
> <u>Counselor</u>: OK, how does this position answer that?
>
> <u>Father</u>: we love him enough to give up some of those things we want. We're willing to do whatever we can for him. We'll have to take things as they come. It's the only way.*

We want the parents to be completely sure that their decision is right. Therefore we ask them to defend their choice to us and to themselves. Dr. Abramson revealed in a Washington Post article:

> Once the family is convinced it's best to stop treatment, I always play devil's advocate. I turn around and attack them for letting their baby die! You told me you want your baby to die! How does that make you feel? Until they're completely ready and able to handle that, and give me the reasons for the decision, I won't act. (Cohen, 1974:10)

6.5. After the Decision is Made

If the decision is to discontinue support care of the infant, we must then work to support parents in this process and

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* excerpt from case study

to support the child in his dying. Because dying is still so difficult and distasteful, unfortunately many parents are abandoned at this point and their babies are shoved off to the darkest corner of the nursery. Indeed it is terrible to watch a baby slowly worsen day after day; however, it is just as important for professionals to continue their caring as it was when vigorous treatment was given. This is because the <u>process</u> is just as important as the <u>process</u> of decision making was all important. What happens during this time can affect parents drastically. We should try to make the effects as positive as possible.

> In most cases dying, like birthing, is a process requiring assistance. It is an event that asks us to be present for one another with heart and mind, bringing not only practical help as necessary, but also extensive awareness and appreciation of the individual involved. At its finest, it elicits from us frankly and fully offered human companionship that brings positive benefits, and a kind of joy to any shared venture. (Stoddard, 1978: 7)

Further, Dr. Mary Kate Davitt, a neonatologist, tells us, "Managing death is just as important as managing illness. It is our job as physicians not to shirk this duty."*

L.J. Weber writes that we have a continued resonsibility after a decision to "Let Die" is made:

> If the decision is made to let die and there is no reason to object to this decision, there is one further responsibility that falls upon the staff. That is the responsibility to care for the dying child as he dies. It is always difficult to care for the dying; it may be the most difficult in the case of an infant whose death is, in a sense, chosen. When no attempts are being made to extend the life of the child, respect for life entails care in the sense of trying to make the child as comfortable as possible and of giving the child as much attention and love as possible. The decision not to treat does not in any way justify neglect. (1976: 109-110)

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*Personal interview, October 1977

We believe that this goes equally for the parents of the dying child. We must continue to love and care for them. We have observed very different atmospheres towards parents once they have made a decision not to treat--even if the staff agrees with their decision. This is becasue it is difficult to be with parents when life-giving efforts are no longer being carried out. For this reason, we must especially be on guard and continue to communicate and be with these parents, even when they come just to look at, hold and be with their dying child.

The following is an excerpt from a case study. The counselor is talking:

> I told the parents that we wanted them to come in to be with their baby, as he was dying. At first Betty [the mother] wasn't sure she could bear that. I expressed my feeling that it would be important for their son, for them, as well as for the staff. "You've made your decision, now you must test it by living with it. We are here to help. We'll continue to meet and talk. This decision was a hard one- -now the next days are going to be harder still." I expressed my admiration for them both and acknowledged the immense difficulty of what they were going through.

In another case a decision was made not to operate on the severely defective heart of a baby who had had major hemorrhaging, virtually destroying the central brain centers. The parents asked that the hand-operated heart pump be taken away, expecting that their daughter would die very soon. She lived for ten days. "We stayed with her," the mother recalled. "The first hour went by and her breath would get very erratic. As the days went by, you could barely see it.

As one might expect, these days of waiting for death are agonizing. These particular parents later told us that even though it had been terrible, they would not have had it any other way. They felt they got some satisfaction from being truly there for their daughter, to love and comfort her as she died.

We do encourage parents to live through their decision by continuing to be with their children as they die. Sometimes this is a long, slow process. Sometimes we expect it to be a matter of minutes after disconnecting a respirator. Parents can choose to be there or not. We do not force them. However, parents who have been through a long process of decision making usually want to continue to have close contact with their child as death approaches.

Helping parents with these decisions is not an easy task, especially because the process demands openness and feelings from each individual who comes in contact with the parents and baby. This hs not been the traditional role of staff people in hospitals by any means. While parents must make these decisions, we must help them. It is essential that we be ready to stand by them, suffer with them, admit to and demonstrate our humanness.

CHAPTER 7

HELPING PREPARE MEDICAL STUDENTS FOR NEONATAL COUNSELING

7.1. Introduction

> In a professional society the young medical student is admired for his research and laboratory work during the first years of medical school while he is at a loss for words when a patient asks him a simple question. (Kubler-Ross 1969:11)

Physicians tell us that they are not prepared to counsel parents of defective newborns or to deal with death and illness on an emotional level. We are not convinved that it is the responsibility of the neonatal department to teach counseling skills to students, nor do we think that this is necessarily the best place to accomplish this teaching. We do think, however, that students need to learn about treating disease in a wholistic manner, and therefore the subject of counseling parents is a natural one to include in the students' neonatal rotations. Additionally, on this service, students are likely to be exposed to life and death decision making and matters for serious moral and ethical consideration. We feel that it is essential that students be given the chance to talk about their own thoughts and feelings regarding these serious issues.

It is important that medical students be concerned with the parents' feelings and social problems as well as with the patient's medical problems. If students are to learn how do do this, we must start by allowing each individual to talk about his own feelings on the subjects of illness, death and dying. We need to allow them the time and space to discuss and begin to form their own ideas about moral and ethical problems in medicine.

Medical students are traditionally taught the scientific side of medicine. Indeed the process by which one becomes a physician in this culture makes it difficult to remain interested and concerned with the emotional aspects of medicine relating to the individual patient. Students work hard. They must constantly digest voluminous scientific data. They hardly have time to breathe or reflect on the more wholistic aspects of medicine. Students have told us:

> I hardly have time to do anything but study and go to school...that's it.
>
> I have to study a lot to keep up. My family life is suffering. I don't know my wife any more.*

A neonatologist said: "I don't recommend anyone becoming a physician. You have to become a zombie to get through medical school and then what good are you? I had to have therapy to open up again after I got through school."**

If we make our potential physicians into "zombies," we are not doing them or ourselves a service. They will be technicians at best. Physicians need hearts, souls and guts to deal with issues as difficult as life and death decision making.

Ultimately the whole edcuation of the medical student will need to change to reflect these realiteis. Perhaps the psychiatric department of each medical school will take more responsibility

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* Personal interview with medical students

** Personal interview with neonatologist for teaching students the clinical aspects of counseling. We believe, however, that this teaching should not be isolated. Each individual service will have to deal with counseling patients and families from their own viewpoint. Pediatrics will need to give training on dealing with children and their parents; geriatrics will deal with their particular problems. Neonatology will have to help students at the time they encounter the unique problems of working in a special care nursery. When each section of the educational system teaches about emotional problems and how to deal with them, it will be easier for the few who are currently trying to manage the entire problem.

For our part, in the Georgetown neonatal service we have tried to think about the issues which come up on this service. Once a week during a three week rotation students meet with the neonatal counselor. The sessions are approximately one and one-half hours in length and are discussion groups rather than lectures. The counselor asks questions and tries to get the students to think and feel about various issues involving parental counseling and life and death decision making. Students are given material to study before the second session which includes literature on the ethical limit in life and death decision making, with particular reference to the neonatal intensive care nursery.

In addition, during medical rounds the neonatologist always brings up the social and emotional aspects of the case to allow the residents and students to think about these problems as well as the strictly medical ones. The neonatal counselor often joins the medical rounds, especially being present when a particularly difficult emotional, moral or ethical problem is at hand.

7.2. A Session with Medical Students

The following section presents one of our special sessions with students to illustrate how we begin introducing the emotional and socal problems encountered on the neonatal ward. Section 7.3. illustrates our teaching during medical rounds.

I met for the second time with a small group of third year medical students. The previous week our session had been about the psychology of parenting. We talked about the students' role in talking to parents of well newborns, what parents need and want to know, what to tell them about caring for their babies, bottle and breast feeding and treating the infant as a real person. We also discussed what babies need for their own emotional health and the emotional health of the family.

I began this session by asking, "Have any of you had any personal experiences with death?" None of the students had close family members who had died. One woman said that her grandfather had died when she was twenty-three. She told us no one had discussed his dying.

"Have any of you had experiences in your training with a patient who died?" One student had not. One student told us that she had been taking care of a man who had died shortly after she changed to a different rotation. She did not know how she felt about it.

One student talked about being involved in a case where a woman was being treated with chemotherapy for a metastisized cancer. She had responded well to the first treatment. Later she was not responding at all. The medical staff expected her to die "soon." The physician in charge left orders that no one was to tell the patient how grave the outlook was. The doctor wanted to tell her only after she was "obviously" dying. She lapsed into a coma hours later and died the next day. The student described being uneasy about the situation and thought perhaps the woman should have been told. He could not have talked to the woman himself because of the medical hierarchy.

We talked about the pros and cons of telling a patient that they are expected to die. We shared the feelings of frustration and helplessness that this situation brings out in us. Many physicians have been taught that their role is one of caring. This teaching only increases the frustration when patients die dispite vigorous medical treatment. It would be helpful for students to know how to care for the dying as well as how to cure.

I asked, "How would you feel about talking to a parent whose infant is expected to die?" There was quite a lot of discussion. One student felt it would be more difficult, one thought it would be a terrifying prospect. "I just don't have the skills to know how to go about that," she said. One student made a distinction between telling an adult patient and parents of a patient. She could not imagine doing it and thought it would be better not to do so. (I thought that her problem with the idea of this must come from some personal difficulty with the issue of death or illness.) I asked if she had any children. "Yes, an eight year old daughter." I asked her to imagine what it would be like if her daughter were sick and dying (admittedly an awful thought.) "Would she want to know? Would you want your daughter to know? Would you want to be able to talk to her about her feelings and your feelings?" These questions she could not answer. I asked her to think about it at home.

A student asked, "What is the line between being realistic and honest with parents so they can come to terms with reality, and when is it scaring them so much that they will reject contact with their child?"

I answered, "I think we can be realistic and at the same time give as much hope as is appropriate to the situation. If we are with parents and support them, I think they can deal with whatever faces them. We have to be willing to spend time and be patient."

The last part of the discussion was regarding the doctor's right to talk to a child with a terminal illness. One student had a friend working under these conditions. We talked about the emotional and the legal aspects of this question. I did not know what the legal implications were in this situation and told them I would try to find out. We talked about what would be psychologically best for all concerned. I said that I could not imagine having one of my kids in that situation and not talking about it. Children have a right to know what's happening to them as well as anyone else. They have a right to be able to work out their feelings and set their affairs in order as well as adults. Generally, most adults tend to treat children differently--not as fully functioning people in their own right.

I later discussed the frustration that being in limbo brings out in parents and staff. We can share our frustration while not giving up hope. We can make human contact when medicine is not meeting our needs. We also briefly discussed a situation of only possible brain damage--how to tell parents about that and what might happen. We discussed the ethics of discontinuing support care. How did they see their roles as physicians in caring for their patients?

There seemed to be low energy expended from two students. The third was more alive and interested and had more experiences and more of his own opinions. On several occasions an answer of "I don't know how I feel or felt" was expressed by one of the students when I asked for their feelings. This seems amazing to me! I hope they go home and think about these questions and come to terms with their feelings as they have more experience.

7.3. An Excerpt from Neonatal Medical Rounds

On our medical rounds, a student gives the medical details for Baby Boy Jones:

> Baby Boy Jones, preterm infant born Thursday, February 10. Chromosome studies have just been returned to us confirming Down's syndrome.

Discussion among the residents and the neonatologist about this situation follows. The neonatologist, Dr. Abramson, says: "What are we going to tell the parents?" (Silence) Dr. Abramson then says:

I want Joe to be the doctor who has to talk to the parents. Phyllis, you can be the mother; Tom, you can be the father. Why don't you two change places so that the "parents" can sit together. Go ahead, Joe.

Joe tries explaining the medical details to the "parents." Afterward, Dr. Abramson asks for feedback.

Dr. Abramson: How did you feel talking to the parents?

Joe: Scared. I didn't know what to say.

Dr. Abramson: Joe, you were having a hard time looking at the "mother." How do you think it would make her feel to be talked to and not looked at?

Joe: Probably like I was afraid to face her.

Phyllis: Well, it's really hard to imagine myself being this mother. When I try, I just don't know what to think. I sort of go blank. My doctor side keeps getting hooked into the technical aspects.

Dr. Abramson: How about you, Tom? How do you feel as the father?

Tom: I'm trying to feel what it would really be like if this was my son. I do have a son who is eighteen months old. When I put him in this kid's place, I just panic.

Dr. Abramson: Do you have anything to add, Pam?

Pam: If I were the mother, I think I'd just tune out all the technical information that you're telling me, Joe. I just can't take that all in or understand it yet. Do you know why you are telling "Me" all that now?

Joe: I just don't know what else I can tell them.

Pam: We know that parents can't assimilate all the medical information at one time. Especially at first. Parents go into a kind of numb shock when they find out their baby is defective. We may have to go very slowly and repeat the information several times. Why don't you try a simple explanation. Also, have you thought of sharing your feelings with them? If you're sad, tell them. (See chapter 2.2.)

Role playing is tried for the second time. Feedback is asked from the participants and observors.

Pam: How do you, as the doctor, feel about telling these parents they have a retarded child?

Some discussion among the participants follows. Hopeless, sad, angry, numb are all feelings brought up by this situation.

> Pam: You know it's really important for us to be in touch with how being around this baby and these parents makes us feel. I know that often I just don't know what to say to parents and I might say, "I just don't know what to say. It's a hard thing you're going through."

Other people then have a chance to be the doctor, the mother and the father. Each time suggestions are made and the participants are asked how they feel in their role.

> Dr. Abramson: I remember the first time I had to talk to parents. I was scared. I really didn't have any idea how to do it and no one was around to give me suggestions. I learned through trial and error. A big part of our job as the baby's doctor is to know how to be with the parents and help them. So think about the rest of the baby's care.

CHAPTER 8

CASES AND COMMENTS

8.1. Introduction

This chapter contains case studies illustrating many of the points discussed in previous chapters. The first case study, the Bebee family, offers an unusually complete account of what happens to a couple with very sick newborns. The first section is the diary kept by Bob Bebee, the father of twins born with hyline membrane disease. The second section contains Bob's comments and reflections eighteen months after the birth. The last section is the counselor's notes, including some tape recorded sessions, taken during and just after the period recorded in the diary. This case gives us a unique opportunity to learn about this type of medical crisis from different angles and perspectives.

The second case study, that of a baby with probable brain damage, is very typical in that the damage is only "probable." During the first few weeks, it is almost impossible to give the parents an absolute answer concerning the suspected damage or its extent. The third case is important because the premature infant was born to a couple with a history of two previous infant deaths. In such instances we must deal with past as well as present situations and feelings. The last case is an example of an early and precise diagnosis. Because the baby was born with an extremely poor chance of survival, we tried to do a lot of work with the parents very quickly.

8.1.1. The Bebees--Father's Diary

Day: Saturday; Date: December 18, 1976

3:00 a.m. Irma goes into labor, contractions about fifteen minutes apart

7:00 a.m. Bob calls Doctor's office, contractions about ten minutes apart

8:30 a.m. Arrive at hospital, Doctor is on duty, admits Irma

11:00 a.m. Heavy labor starts for Irma

12:30 p.m. Bob changes into hospital clothes

1:10 p.m. We go into delivery room

1:34 p.m. Girl is born by natural means

1:35 p.m. To everyone's surprise another baby is discovered

1:41 p.m. A boy is born

4:10 p.m. Babies (twins) are taken to Georgetown Medical Center. Both children are suffering from hyline membrane disease.

Day: Sunday; Date: December 19, 1976

Both children are up and down, incubator at one-hundred per cent O_2 intake, girl is in better condition than boy, though both are critical. The boy's oxygen level went to a dangerous level at 6:00 a.m., both seem to be improving by 8:00 a.m. 11:30 p.m. the boy's right lower lung burst and a tube had to be placed into outer sack. The theory is to draw any excess O_2 out of outer sack to let O_2 be absorbed in system.

Situation remains grave. I quietly went to church and prayed for their recovery. The doctors say to expect anything and it is too early to have much hope, only do all that medically can be done.

COMMENT:

As you can see in Monday's record, there are multiple entries as the father checks on the children through the afternoon. It is not unusual for sick babies to be improving, as Bob records at 3:00 p.m. amd worsening five hours later as he reports at 8:00 p.m. This causes its own particular kind of stress for the parents.

Day: Monday; Date: December 20, 1976

1:00 a.m. Bob arrives at Georgetown to see twins. The girl is steadily improving at eighty-seven per cent O_2 intake by tube, but the boy is worse.

3:00 a.m. Blood gases get worse on boy, more tests and X-rays taken.

5:00 a.m. More IV's and blood given, situation more grave.

8:00 a.m. Bob leaves for hospital at Arlington, boy has stabilized and girl is still improving. Boy is on Curari to be kept still.

3:00 p.m. (call) Girl is fine, boy is improving (named Bryan Stuart).

8:00 p.m. (call) Girl is fine, boy is getting worse.

11:00 p.m. (call) Boy stable but not in good shape. I pray my son makes it through the night. I love him.

Day: Tuesday; Date: December 21, 1976

9:00 a.m. (call) Girl improving, boy had a rough night, as second tube had to be placed in the chest.

3:00 p.m. (call) Girl is down to nasel C-pap and thirty-eight percent O_2 and has kicked out two IV's today, could be a problem. Boy also has improved and is down to fifty-seven percent O_2 but still on C-Pap.

9:30 p.m. Bob visits. Girl looks very good, boy had just kicked his chest tube out and it was two hours before he stabilized. After seeing them I drove over to Arlington Hospital and after eliminating twelve names came up with Bridgette.

P.S. I handed out cigars this afternoon. Everyone at work is pulling for the kids to pull through. I pray to God they do, too.

COMMENT:

For both Monday and Tuesday, Bob writes that he had driven to another hospital. The twins were born at Arlington Hospital and transferred to Georgetown Hospital. The mother was left at Arlington. This puts the Father under additional stress, because he must drive from one hospital to another in order to see his children and his wife. The mother typically has a difficult time getting information about her children and cannot even see them for several days. When possible a counselor should go to the mother's hopsital in order to talk to the parents together. Further, we recommend that both the mother and the baby or babies be cared for in the same hospital. If the baby(ies) must be transferred, the mother should be transferred with them.

Day: Wednesday; Date: December 22, 1976

I picked Irma up at the Arlington Hospital and brought her to Georgetown University's ICN [Intensive Care Nursery] to see the children for the actual first "real" time. She could not get over how long they were. Bryan was doing much better on forty-five percent O_2 and Bridgette was down to thirty-five per cent O_2 and the nasal breathing aid. Both are being fed by IV's for strength. The doctor told Irma to keep working on breast milk for feeding.

After the visit we had an appointment with the prenatal care advisor [counselor] and the doctor. It was quite a session. They brought both of our fears out of us about being parents of twins and the problems of defective children and how to handle it. [See Chapter 8.1.3.] We visited the twins again just before we left. It was a relief to see them doing so well.

Day: Thursday; Date: December 23, 1976

10:00 a.m. (call) Rejoice Bryan had an uneventful night, no serious problems. In his case even no improvement is good news compared to the "good" days and nightmarish nights he has had. Bridgette is still improving ever so slowly but surely. Today the C-Pap was discontinued. She is now at thirty per cent O_2 directly into the isolette.

6:00 p.m. (call) Bridgette is under the biliruben light for slight case of jaundice and is expected to be for several days. She is so young that once in a while she actually forgets to breathe or have a heart beat and must be stimulated. Bryan's breathing on his own but still getting help and still accumulating oxygen in his chest which may beam a hole in the heart which will take time to heal, but is down to thirty-seven percent O_2. I'm afraid to call tonight because they are doing so well and we need this sleep, so I'll let Irma know all is fine. Tomorrow we visit with presents.

Day: Friday; Date: December 23, 1976

Today we visited the twins, arriving at 12:00 noon. When we walked in they were operating on Bryan. Our hearts sank. Though they were only placing an IV into the jugular vein it scared both of us "to death." Bryan had another uneventful day which was terrific, also his O_2 level is down to thirty-three per cent and automatic breather at forty b/m and he came off the bilirubin, color is good and reflexes have picked up.

Bridgette is coming along well, she is off the C-Pap and at twenty-seven per cent O_2. Her color lost, though, and she is on the bilirubin lights. You should see her facial expressions when they poke for blood. She has her mother's characteristics of rounder face and sharp jawline. Bryan looks more like his father.

We brought them little Winnie the Poo bears and stockings, with a snowman for Bridgette and a Saint Nick for Bryan. On the way home Irma and I both broke out crying with the thought of them in incubators on Christmas Eve.

Day: Saturday; Date: Christmas 1976: No entry.

Day: Sunday; Date: December 26, 1976: No entry.

Day: Monday; Date: December 27, 1976: No entry.

Day: Tuesday; Date: December 28, 1976: No entry.

Day: Wednesday; Date: December 29, 1976

10:15 p.m. Bryan doing pretty well--blood gases stable. (Robin) at thirty-one per cent 19-20 cc, color good. Lungs were a little clearer. Leaves one tube still in the chest.

COMMENT:

In the next entry, the father talks about his frustration and anger, for the first time. The boy had been doing better and suddenly he has a serious setback. Their reactions are normal. Bob's desire to "kick the shit out of someone" shows the intensity of his pain and anger. (See chapter 2.2.)

Day: Thursday; Date: December 30, 1976

Went to see the twins about 7:00 p.m. with Ann and Irma. Bridgette looked well, Bryan, too. The scanner showed that there had been bleeding in the ventrical passages. It's still too early to tell what damage is done.

It is so frustrating. Nothing to do but wait and it's driving Irma and I up the wall! Sometimes I feel like kicking the shit out of someone. We went to see Clint Eastwood in "The Enforcer." It felt good to see them all relieve some tension.

COMMENT:

In the following two entries, Bob writes about the sleepless nights of hell and the frustrating, unimaginable days that parents of defective newborns experience. We, who are making contact with these parents, must always keep in mind the suffering they are going through.

Day: Friday; Date: December 31, 1976

8:00 p.m. Bridgette's heart and breathing stopped. Last night was hell--we did not sleep.

Day: Saturday; Date: January 1, 1977

Bryan stable and Bridgette seems well. It seems this happens every so often. I think I've aged a year every time I call, but at least I know what's happening.

Day: Sunday; Date: January 2, 1977

Bryan breathing on his own but had to go up thirty-two percent. Color is good, gases are not real sure at this point.

Bridgette fine now, eating three cc, one every other time.

Day: Tuesday; Date: January 4, 1977

Bridgette is "no tricks"--fine.

Bryan down thirty per cent oxygen cut resp. five per cent, color is pink and his eyes are open. Will do no more changes tonight, blood looks fine.

Day: Monday; Date: January 10, 1977

Linda said Bryan is stable tonight.

Bridgette is up to fifty grams, twenty cc of food.

COMMENT:

Bob discontinued keeping an orderly diary at this point. Too many painful and disorienting things were happening. The boy worsened and a decision was made, with the parents' help, to discontinue support care. On February 5, Bob and Irma came into the hospital to be with their son as the respirator was turned off.

The following section contains this father's comments and recollections of the ordeal, written one and one-half years later.

NOTE:

As linguist Georgia Fuller pointed out, Bob's diary immediately records his "emersion" into hospital routine and medical language (e.g. hyline membrane disease, lung burst, outer sack, O_2 intake, nasel C-pap). Because these phrases were new to him and because they were numerous and combine with a radically different routine, he probably did not understand completely the terms in which he was suddenly forced to communicate. This undoubtedly added to his stress.

The changed linguistic and cultural environment, in and of itself, is not unlike total emersion into a foreign language and culture. In the psycholinguistic and language learning literature, the stress caused by such a change is called "anomie" (Jakobivits 1970). Anomie is a feeling of social estrangement, disorientation and rootlessness--a separation from the world one had assumed to be "real" and an encounter with a new, bewildering, even threatening "reality." According to Dr. Fuller, "Anomie can combine with the anxieties of a life-and-death situation to produce extreme stress for the parents of defective newborns. One way hospital personnel can help reduce this stress is to look on themselves as friendly native guides and interpreters--explaining hospital routine and procedures and medical terminology as often as necessary and in terms as familiar as possible to the parents."*

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* Personal interview with Georgia Whippo Fuller, Ph. D.

8.1.2. The Bebees--Father's Reflections

June 1, 1978

Well, it's now almost one and one-half years since the kids were born. Sometimes it feels like yesterday and other times it's a mixture between numbness and pain. Last night I ran into my company commander from Vietnam. It's funny, I had a difficult time remembering; as if my mind had set up a roadblock. I've suddenly realized why I've only kept notes and never put anything into a full diary. I think I was afraid to be able to pick up and see exactly how I felt at a particular moment. I would have had a hard time handling it.

I'll never forget the night of February 1st. Bryan had turned worse for the second time and it was apparent something had to be done. His little hands started to curl under and I knew he had suffered enough. I had asked (Irma mostly) for a baptism for Bryan. The minister said that he was still a child of God and had not yet sinned. I wanted it in the church record.

The period between their birth and February 1, 1977, was relatively easy. I had seen death in Vietnam and even though Bryan was mine, I could feel distant as I had when I left a friend overseas. But now the numbness was wearing off. Bryan was my son and as a father I had to have the strength to let go. It took two days to prepare Irma.

I called my folks to come down for the second time and the night of February 5, 1977 Irma and I went in.

I had many close contacts with God, first as a child with my heart problem, then when they thought Irma might die because of a blood clot in 1972 and then during her pregnancy. I feel good now knowing Bryan will not have to spend the rest of his life captured in a body and not be able to use it and never know the pain of not being able to live like other kids.

Except for a few times, I have been able to handle it all. God will always be with us and always watch over Bridgette. Except for some periods, like in February, I saw a set of nine month old twins in Penny's and got so depressed that I did not work for the next two days.

Valentine's Day and Christmas were the "pits" but we had to force joy for Bridgette's sake.

Every day gets a little better. Bridgette gets a little more personality and Irma is more herself.

Irma and my situation as a married couple has gone through the wringer. I can see why couples split when things like this happen.

People would rather run, than to face it. I believe that for a while the only thing that kept us together was the baby but not for the baby. It was Irma not wanting the baby to feel left out and not knowing her mother as Irma has felt for most of her life and my feeling of wanting to be the father that has kept us married. The other was both of our parents being out of the picture. This was something we had to face alone. The last point was that we had been married almost six years before this happened. If it had been earlier I do not really know what would have happened.

The nurse helped us take the respirator off and Irma and I held him. He was so tiny but there was a sigh and he felt relaxed as we were holding him before the O_2 was cut off. He was so precious. I felt so empty. He went into a coma. Irma said good-by and left. She could not handle it. I had to wait to make myself see that my decision was right by seeing that he did not suffer. A nurse came in to rattle some sterile water bottles. She had been at the door waiting. I guess it took too long for him to die and she came in. I asked her to leave and she was a little indignant but left. Honest, I would have thrown her through the door (closed) if it wasn't for Bridgette in the other room.

Up until his death Irma had felt that God had punished her because she was not yet ready to have kids. She felt that God gave her two and took the one she favored (Bryan) as a punishment. (See chapter 5.)

Both of us found it hard to relate to Bridgette. It was as if we had to feel guilty for sharing joy with her because we could not be with him.

Dr. Davitt did the best thing by letting Bridgette stay in the hospital an extra week. How do you describe the pain and joy at the same time--you have two kids and one dies and one lives.

The last year and a half have been hell. I now believe that Hell is here on earth and Heaven is after death. My belief of a spiritual afterlife has been the only thing keeping me from insanity. It has been easier for me than Irma. I talk a lot and I see people every day. Irma does not.

The house is finally getting clean after a year, but I can appreciate that. Many nights I would come home to know nothing was done. I knew Irma just sat and stared.

For many months we would just talk at each other. We loved each other but were too tired after giving Bridgitte all we had. Then slowly since Janary of this year, each day got a little better. I'd say that we are now at about the same level as before Irma got pregnant.

Pam, you have the transcript of the tapes and our worse feelings were brought out only when you were around. We had several blow-ups but about nothing different. I honestly feel that with the exception of the financial strain we have a very viable and happy marriage. Irma gets cutting sometimes and I ignore what she says, sometimes, but all in all, things are very good. Things have happened through counseling and I can do things now that I could not do before.

1. To cry when I feel sad.
2. Not feel embarrassed when my baby does something in public.
3. Be able to talk about Bryan as though he is dead, and not like he's still alive.

4. Not give a damn what people think. One important thing is we lost several friends which we really did not need. Only the best stayed on because they cared.

5. Be able to tell Irma what's really bothering me at the time instead of ignoring it. Irma still does it a little.

6. Not blaming someone else for something I did when I know I did it.

7. Just being happy every day when I wake up and see my daughter and a new day.

To fathers I say this: find a baby sitter and take your wife somewhere. Help handle the kid and do not use work as a cop-out. We as fathers really have it easy. We have work and other activities to escape to. Where can wives go? No matter what they say, the women will always feel that they gave birth, and if the children are not A-OK it was something they might have done during pregnancy. That is the most quiet Hell thay can have.

To sum it up andask was it worth it? At this point I still cannot answer that. I love my daughter deeply, but to have gone through this, I do not honestly know. Only time will tell.

8.1.3. The Bebees -- Counselor's Notes

The following is the counselor's report on what transpired this time with these same parents. The second session, which was tape recorded, is included in its entirety so that the reader might better understand what the parents are going through and what the counselor was trying to accomplish.

The Bebees

Tuesday, December 21, 1976

HISTORY:

Premature twins, transferred over the last weekend from Arlington. Dr. Siva asked if I would come in tomorrow especially to see these parents. Mother still at Arlington and should be leaving tonight or tomorrow morning. One baby (female) on respirator doing well (for premi on a respirator). The other twin (male) very poor. Had period of five to six hours of hypoxia. Dr. Siva suspected brain damage. Unknown prognosis. He hinted that we might have a potential decision to make at a later time with this baby.

Parents are in their mid-twenties and these are their first children. Mother had a very difficult pregnancy. The resident in charge has asked if a psychiatric consultation was in order for the father. I could not find reports of any behavior which would warrant this when talking to the nurses.

The father had spent a long period of time in the nursery with the babies, particularly the boy, during the time the baby was very ill. He cried several times. I think the resident is very uncomfortable with really strong feelings. (See chapters 2.1. and 3.2.)

COMMENT:

It is common for a major medical center to have infants brought in for specialized treatment who were born in other hospitals leaving the mother at the hospital where she delivered. She cannot see her baby during these first few days and has difficulty getting information.

As noted in 8.1.1., the father has to dash madly from one hospital to another in order to be with both wife and child. The staff must be aware of the unusual stress put on parents at this time and try particularly hard to help in whatever way possible.

December 22, 1976

First Session: Irma and Bob Bebee, counselor and neonatologist. (See chapter 8.1.1., December 22, for Father's diary entry)

Twins are four days old. Mother's first day out of the hospital. Dealt with fear of twins dying and that the baby boy might live but be damaged. Irma confessed that she did not want a baby in the first place. Dealt with guilt--the father pushing pregnancy on his wife selfishly and the mother's not wanting it. God is punishing her for not wanting the babies! Opening up communication and expressing feelings to each other. Parents began to do this. Bob was surprised by his wife's feelings.

COMMENT:

This was a typical session in that feelings were expressed for the first time. The mother, especially, mentioned feelings previously not shared with her husband. (The issue of guilt appears right away as well as the fact that the parents had been having a difficult time communicating.) It is common for parents to be wide open and quite vulnerable after the birth of a child and especially when the situation is trying and very emotional.

Second Session

Expressed that the first session had been helpful. Dealt mainly with Irma's fear that she would run away or withdraw if anything happened to the babies--this being her normal defense pattern. Bob expressing that he thought she would run to Mommy. I asked him to ask for something. He wanted her to come to him instead of to her mother, "now it's us." Most of the last part of the session was spent in making his needs known and trying to obtain a contract from Irma to stay and work things out with Bob. Bob was scared and angry that she might run.

We did not need to provide much medical information because they had been in close contact with the nursery.

[Following is the transcript of the second session with the Bebees.]

(Bob had been talking about shopping and splitting the responsibility with Irma.)

Bob: As minor as it seems until the other day I would have been afraid to mention it to her.

Pam: How about some of the more difficult things you've had to talk about the past few days?

Irma: The news spread like hot fire. I talked to a lot of people. If they (the babies) aren't okay, I'd like to take off...run away. If I accept the situation, it will be hard. (here Irma cries--long pause.)

Pam: Could you be more specific? What do you mean by the "situation?"

Irma: If one of the kids dies(long pause) I tell myself it's God's will (more crying), I ask myself, "Am I really as strong as I think I am?"

COMMENT: In the following lines, Irma talks about wanting to take off, to run away, to deny what's happening. This is a typical early reaction to a crisis, as discussed in chapter 2.2.

Pam: Do you have ideas--fantasies--about what might happen to you?

Irma: I'll "take off" but that won't solve it. Bob will say, "What about me?" I see Bob as maybe a little stronger than I am.

Pam: What would be the worst thing that you could think of that would happen to you if something is wrong with one of the kids?

Irma: I don't know if I would try to escape (pause), not go off the deep end, but just try to block everything out. (pause) Live in a dream world instead of being realistic. That bothers me.

Pam: Can you get help from Bob?

Irma: My attitude is that he has enough problems of his own. (pause) Even though Bob is my husband, I feel he has other things. If I can deal with it or push it away on the side, then I'll do that. I'll say well, "that's life" or "that's the way the cookie crumbles," pretend that everything will be okay.

COMMENT:

At the previous session Irma had confessed to Bob that she really did not want children at all. She was doing it for him and she resented it and was angry. Previously she had kept it from him to protect him, she explained. This is referred to in the following exchange. Then Irma talks about God punishing her, a common feeling discussed in chapter 5.

Pam: How about right now, Irma? Is there anything that you're keeping from him becasue you're trying to protect him?

Irma: I think I told him everything. (long pause) When I look back (pause) with him knowing that I didn't want kids, then with everything turning into a complete nightmare with me physically, then going ahead (with the pregnancy) because it was my only chance. (pause) First we were working on just one child. (pause) God knew that I really did not want a child and I don't know now that He said, well, since you didn't want one, I'll give you two.

COMMENT:

Irma then talks about wanting a boy very badly. Her family was mostly girls. It first appeared she wanted the boy for her parents.

Irma: The feeling I had when the girl was born--my temperature when they told me it was a girl--it would have zoomed! I thought there's nothing I can do about it now, she's here, and then there was a big difference when they told me there was another one and it was a boy.

Pam: It's important to continue your communications with each other. (pause) If something does happen to one of the twins, we don't want you to withdraw and use your old defenses. You'll need each other then.

COMMENT:

At this point Bob breaks into the dialogue to bring up something which has bothered him for years. The counselor tries to get him to talk to Irma about it--not just report it. It is important for us to get parents to communicate with each other.

Bob: I'll tell you something which bothers me. I've never really brought it up. (pause) Irma left home at fifteen. (He goes on to explain where she went to school, etc.)...She's always felt an alienation from her parents. I think she tries to please them. She refers to her mother as "mommy." When she talks about wanting a boy I think she wants to please her mother because her mother wanted more boys--I want it to be from Irma not because she wants it.

Pam: Tell Irma (gesturing towards Irma) (pause); talk to her.

Bob: I want it to be from you not because you want to please your mother or father. (Bob continues) Now that we are married, we are us. (pause) It bothers me when I hear you want to please them.

(Bob gives example of bringing a sister to live with them. He called it a strain on the marriage, but did it because Irma wanted to please her parents. Discussion continues with Irma about her parents. She states that she wanted a boy more for Bob.)

Pam: My sense is that this is really garbled. Can you be straighter with Irma about how you feel?

Bob: I'm not being very straight? (pause)

Pam: My guess is that you are pissed off.

Bob: I'm not pissed off--I'm just a little agitated.

Pam: (laughter) Semantics!

Bob: (laughs) I never really get angry at people! (laughter) Really, yes, I get that way with my parents.

COMMENT: It is difficult to keep them zeroed in on the communication. In the preceding and following lines, notice how the counselor must work to bring them back to the issue at hand.

Pam: To cut down the words--see if you can just ask her for something that you want for yourself. (pause) What do you want?

Irma: My parents aren't even here.

Bob: They don't have to be. I can read it in you. (pause) I look for stronger communication between us. I don't mean to alienate.

Pam: Don't apologize.

Bob: OK. As far as your parents are concerned, I feel more of a mental block with your parents than I do with the physical stuff with my parents.

Pam: What do you want?

Bob: I want more the mental need--to me than just some of the physical things. Do you understand?

Irma: What do you mean, mental?

Bob: Sometimes I feel mentally adrift from you. I feel more of a mental block with a fence that you're putting up with your parents than you do with the physical shit that my parents give us. I can mentally shut them off and I'm still with you but I don't always feel that with you and your parents.

Pam: I'd like to say what I'm hearing. You want to say to Irma, "I want you to run to me instead of to your parents when the going gets rough." (pause) "If something happens to the babies, I want you to come to me for support."

Bob: (breaks in) Yes, every time you withdraw I feel like you'd rather be home talking to your Mom than to me.

Irma: Not talking to her--just getting away from here.

Bob: Why not run to me and let's run together? That's what it's all about.

Irma: Maybe all the time I'm feeling--selfish--forgetting about you (sad) at the time and just want out of this, to get away from it all. Not realizing that you feel just as bad as I do and would like to get away, too.

Bob: How do you know?

Irma: I don't know, I never asked you.

Bob: You're always the one.

Irma: Right, I always have my bags packed. I've always said you go back to your parents and I'll go back to mine.

Pam: After six years, that gets cold.

COMMENT:

In the preceeding and following sections note that old family problems arise and need to be aired. This is typical.

Discussion between Bob and Irma indicates both are still tied to their parents. Bob said not on his side, but from his mother. Irma wants Bob to tell his mother to go to hell. Bob tells us that his mother is schizophrenic and a big family problem, that he tolerates her. This goes on.

Pam: (cuts in) OK. I'm hearing the same thing from both of you (pause), which is: "I want more of you." (to Bob): I hear you saying it. "I want all of you. I want you to give up your parents." I understand that we never give up our parents completely. That is basically what I'm hearing. (pause) You can talk a lot about this. I think you need to go home and continue talking about it. We can't resolve it here this minute.

Bob: Since our last meeting I did one thing you didn't know about. I called and told my parents that they could not come down here at this time. I said we need each other now. Outside people would make it harder right now.

Dr. Siva: As Pam said, this is a matter to continue discussing at home.

Pam: It sounds like there's some anger on both your parts about your parents.

Bob: Going back to the main thing of Irma running, I want to make sure you run to me and that you won't go into yourself when the babies get home. If we do have a problem with Bryan we need to fight it out together.

Pam: That's essential. You've just asked for something. (to Irma) I wonder if you're willing to make a commitment to Bob (pause)...Could you say, "Maybe I want to run, maybe I want to go home to Mom, I want to withdraw, but I'm going to tell you about it and I want to deal with it?"

COMMENT:

In the preceding and following exchanges, the counselor is working to get them to agree on a method of action that is more positive than running away.

Irma: I don't think I'd have the heart to run if something was wrong when they came home and say to Bob, "They're your responsibility, now you deal with it."

Bob: That bothers me. I want it to be because you want to stay, not because you think you should or because you're guilty.

(Discussion between Irma and Bob follows about her motives. She says she can't cross that bridge before she comes to it.)

Pam: There's a slight difference here. Bob's asking for a commitment to work on the problems. What I'm suggesting is to plan to work it out whatever the outcome. We don't know what will happen.

Bob: I'm trying to lay the groundwork for negotiations while there's a third person here. (pause) Sometimes I can't get it out. I beat around the bush or mumble or not be straight (pause). I thought I had to be strong and love Irma and kind of protect her. Now I want to get things straight and know that it's [my love is] recognized. With the twins it's important to work things out. I think they can feel it when we aren't working together, and I'm a strong believer in emotional transference. It's important to me to work it out before they come home.

(Bob rambles on a while more.)

Pam: Is this your usual pattern of talking?

COMMENT:

Here the counselor tries to point out to Bob that he is rambling. It is confusing. Her purpose is to help the parents improve their communication.

Bob: I don't know. (to Irma) Is this?

Irma: I tell him to spit it out! I don't have all day to listen.

Pam: OK, that is exactly what my reaction is. You have a lot of words for what you are trying to say. I suggest again that you ask Irma for what you want. (long pause) (To Irma) Bob's asking for you not to withdraw and you haven't given him a straight answer.

Irma: Well, I don't know.

Pam: That would make me real nervous, if I were Bob.

Bob: God damned right it makes me very uptight! (looking at the counselor)

Pam: Tell her.

(Bob repeats himself)

Irma: I am positive that I won't leave.

(More discussion and finally Irma says she'll get help from a counselor if needed.)

COMMENT:

At this point, the counselor repeats the agreement so that it is clarified. As we have discussed, that is always important.

Pam: So you are saying that you are willing to make a commitment to work it out, to deal with it, to get a counselor if necessary?

Irma: Right, I'll try.

(Session continues a bit longer with some discussion about the importance of rest, sleep, eating good food and continuing their communication. Another session is set for four days hence.)

COMMENT:

As we have commented throughout this session and elsewhere, previous problems regarding family and relationships often have to be dealt with along with the crisis at hand. Family problems are very real and certainly must not be disregarded at this time.

Third Session

New face: Dr. Davitt, the Bebees, and the counselor. Both babies improving.

Parents started talking about Bob's mother coming, possibly the following day. Bob's mother is ill, according to Bob she is a "schizophrenic," sometimes nice and sometimes impossible. Tales of the problems and how they were solved or not were related. It became obvious that Irma took personally whatever Bob's mother said or did. They continued to be at odds about how to deal with her. Irma wanted Bob to tell his mother to "shut up" or "go to hell" and Bob said to ignore or humor her. Irma felt put down by Bob's parents because of her background. "Not blonde and blue eyed. (She is from Honduras.) She was also afraid the children would be put down because of their heritage.

I tried to suggest that they had better deal with "Mom" together and made the analogy that they would have to learn to work together to be parents. I told them of my experience with my children and that children know how to work both ends against the middle. My guess would be that Bob's mother could wreck havoc with their family and especially with the new babies.

COMMENT:

The two neonatologists in our hospital rotated on and off the neonatal intensive care unit every three weeks. Therefore, after working with Dr. Siva, Mr and Mrs. Bebee are now faced with a new physician. We feel that because of this it is even more important to have one person, in this case the counselor, follow through with the parents.

Session Four

Dr. Davitt and the Bebees.

Thursday the baby boy took a severe negative turn. I was on vacation and Dr. Davitt met with the Bebees to explain the situation. The girl had also had a setback although not as severe.

Bryan (the infant) had an interventricular bleed after which he also had several seizures. At that time Dr. Davitt was very negative about his ultimate outcome and began talking about the possible need for a decision to stop care. Bryan's oxygen need also increased to ninety per cent.

Dr. Davitt reported that the parents were very upset and acting appropriately.

COMMENT:

During the fourth and fifth sessions, the worsening condition of the twins was explained and discussed.

We believe that it is essential to keep parents informed about their baby's condition at all times. We also find it helpful to tell parents our own thoughts on the matter. We want to give them as much time as possible to assimilate what is happening. We must not face the parents with any more surprises than are absolutely necessary. Sick and premature infants are unpredictable enough.

Session Five

Monday. Medically Bryan has stabilized. The outlook is poor but unsure. Bridgette has a potential hydrocephalic problem. Dr. Davitt is not ready to give up on Bryan.

The outlook as I see it:

1. Bryan may worsen and die on his own.
2. We may have to make the decision to stop.
3. He may remain stable, come off the respirator and be retarded, damaged.
4. He may not wean off the respirator. The degree of damage is impossible to say.

Dr. Davitt thinks maybe there is a ten per cent chance that he would be "normal" if he survives.

Session with Dr. Davitt, the Bebees, and the Counselor

Very difficult to keep Bob particularly on track. He was scattered, frustrated and angry. He focused his anger on a doctor (now deceased), Irma's obstetrician before she became pregnant with twins. What he wanted to say was that if he'd known that things would turn out so badly he wouldn't have wanted the pregnancy or continued with it.

It was difficult for him to see this, but he finally agreed and admitted anger and frustration.

We talked about where they thought they were medically. Irma answered not wanting to admit the worst (retardation). She cried. I asked them if they had talked about a possible decision and if they thought they could make it if necessary.

Again, Irma brought up wanting the boy and we talked about that and the worst possibility of having neither. Bob said his sadness was tempered with the hope of one normal baby.

I asked what they needed from each other and what they needed from us. Bob's fear was that Irma would withdraw, "sit in a chair and stare straight ahead, not talk," and that he wouldn't be able to handle it.

I emphasized the importance of keeping the communication going and the feelings out in the open. "If you do you won't sit and stare." I told them that they could call on us at any time if either felt something that couldn't be dealt with. Bob expressed gratitude for the sessions, that he already felt a change in their relationship.

It took us thirty minutes in the beginning to cut through the bullshit, to let Bob ramble before he could get serious. I pointed that out and asked for both of us to be aware of it for the next time.

Another session is scheduled for Friday.

8.2 BABY WITH PROBABLE BRAIN DAMAGE

Medical information: Baby born Loudon County; Baby girl Smith; Six days old today, June 14. Term; uneventful pregnancy. Monitored--emergency C-Section for fetal distress meconium fluid; aspiration; seizures for seventy-two hours; subsided with treatment. Baby now off the respirator.

Mom and Dad are in the late twenties. First baby after an infertility problem. Mom pumping her breasts and getting a fair amount of milk. Parents have been in daily since Mom got out of hospital. There is to be a consultation with Dr. Kennedy, who is the brain specialist; an EEG is planned.

COMMENT:

The typical problem in this type of case is that even a normal brain EEG does not guarantee a normal brain. We therefore have a situation in which the damage to the child is unknown. The unknown factor is usually the most difficult part for parents and it is more typical of these situations. It causes great frustration and anger, especially if the baby had been perfectly healthy before birth. In this case, the frustration and anger are increased because the child had been planned and hoped for. Typically parents ask, "Why us?" and need to discuss their fears and needs of mutual support, as well as the medical information.

First Meeting with Mr. and Mrs. Smith

Present: Dr. Davitt, the Smiths and the counselor.

Clinically, baby is doing well, EEG normal. We discover right away that Mrs. Smith is a remedial reading teacher. She has had lots of experience with slow learners, retarded kids and kids with perceptual handicaps. The Smiths are intelligent and communicate well with each other, including emotional communication. They apparently have been talking about problems already.

Baby Smith is doing well clinically and we are hopeful and also cautious. We talk about their worst fears and the feelings they have about what has happened and what the future holds. We talk about the importance of emotional communication with each other. They appear to be a happy, loving couple who are relaxed about life, usually.

Mom talks more and uses her talking to keep from feeling sad or scared sometimes. Father is less talkative and more subdued.

Mom inappropriately smiling and laughing at times. They both express deep love for their daughter "no matter what." Mom has already checked out a school for handicapped children. They ask about infant stimulation programs and are willing to drive to Georgetown (one and one-half hours) to participate. Both were teary-eyed at times.

We explained the importance of treating the baby normally with the possible exception of added stimulation, carrying, holding and talking to the baby.

(time--one hour, twenty minutes)

Later next day:

I spoke to Mr. Smith when he brought milk in for the baby. He seemed okay.

Days later:

I spoke informally to Mrs. Smith in the transitional nursery just before she was to take the baby home. She seemed very excited and happy to be going home. The baby was breastfeeding well and was to outgrow slowly the medication she was on.

NOTE:

Klaus and Kennel (1977) believe that it is best not to alert parents to suspected damage or mental retardation. They feel that hospital personnel should be one hundred percent sure before discussing the issue. In our experience, one hundred percent certainty is almost an impossibility. In addition, almost all parents, even those with limited medical understanding, suspect damage or retardation simply because their baby is receiving specialized treatment. We have found that they already have a "worst possible fear" and frank discussion is the best way to deal with it. In this particular case, the parents, themselves, had thought about the possibility of mental retardation and were looking for ways to respond positively.

8.3. SICK PREMATURE INFANT

Parents' History of Two Other Infant Deaths

History:

Two years ago these parents had a premature infant die with hyline membrane disease. Ten months ago they had a still born child born at six months fetal development. Both of these children were born at other hospitals.

Obviously parents really want a child. They went right ahead and got pregnant after only a couple of months of waiting this time. I wonder if they have dealt with the death of their still born infant. Because this pregnancy followed the other so quickly, I wonder if these parents had enough mourning time.

We know the potential problem with this couple so the neonatologist asked me to speak to the mother right away.

First Session

Spoke to the mother, Mrs. Frankel. She spoke easily with no prodding. She seemed open and glad to have someone to talk to.

She gave me the history of the first two experiences without my asking. The first experience was horrendous, she related. She was not, she felt, treated with compassion. She was told that the baby had a seventy percent chance of surviving. The next morning the doctor said he had told her twenty percent.

COMMENT:

What is real here and what did the mother want to hear? This is an example of the need to repeat information several times and to check with the parents to find out what they heard. (See Chapter 6)

Mrs. Frankel also reported that the nurses treated her "poorly." She said that one "forced" her to go to the well baby nursery to see the babies after hers had died. She said that the doctors did not explain the tests for the baby or get permission for the blood transfusion. She thought the blood transfusion killed the baby as "they gave too much blood to the baby, then he had a cerebral hemorrhage."

We cannot be sure what is real and what is distortion. It is obvious that these parents were not counseled and should have been. The mother was still carrying a lot of sadness, anger and resentment about the first baby. These problems might have been avoided if she had been given time to talk things out with her doctor or a counselor. They must be dealt with now, along with the current crisis.

Mother told me that a lawsuit is current about this first birth.

COMMENT:

Law suits are not an uncommon way for parents to vent their unresolved mourning feelings of hostility, anger, sadness, frustration and fear. Would this be different if parents were given time, energy and caring at the time of their crisis? We have reason to think it would. We do not know of one case where parents wanted to bring a suit when they were given adequate time and energy. We had one situation in which we told parents that a mistake had been made (they could bring suit if they wished). The parents' reply was: "You have been honest with us all along. You have given us time and caring. You have tried your best. What more can we ask?"

Mr. and Mrs. Frankel's second child died in utero. They had not seen either child. Mrs. Frankel told me that both of them were terrified that this baby would die also.

COMMENT:

This is a typical response with parents who have lost another infant. As noted, we should expect this and pay particular attention to parents with this history.

During this first visit I mainly listened. However, I did talk to Mrs. Frankel about her fear that this baby might die also. I explained that it was normal for these old feelings to come up now. I suggested that she feel them and talk to her husband about them. I emphasized the importance of communicating with her husband and he with her. "Don't let these old feelings scare you too much," I said. "Allow yourself to feel them."

Second Session

Both Mr. and Mrs. Frankel, the next day.

Mr. Frankel's parents had disowned him when he married, as she was a divorced woman. His parents are orthodox Jews. Mrs. Frankel said, "He seems very depressed about their relationship or lack of it." Mr. Frankel was more reluctant to talk than Mrs. Frankel.

Mr. Frankel said, "My parents told me that our first baby could rot in Hell." He reported that he had visited the first baby's grave. "I'm afraid it was my fault that our second baby died." He reported that he did not go to the grave the last time.

I told them to communicate, see the baby, etc.

COMMENT:

There was an unspoken assumption that this baby should be healthy. Because he was not, tremendous guilt was felt by the father:

1. for marrying a divorced woman.
2. for visiting the grave.
3. going against God's laws (See chapter 5)
4. going against his parents' wishes.

Following day: A.M., Baby is better. Off C-Pap, off umbilical catheter, Mother and Father went to nursery to see the baby last evening. Father took pictures of the baby and touched the baby.

P.M. I walked down to the nursery with the parents. Mother seems relieved, father still depressed, talks in a monotone. He is scared and does not trust the situation. He is taking a lot of pictures. We talked about where they are emotionally and where the baby is physically. Baby is doing fine now.

Later that week: Dad back to work. Spoke to mother in the nursery. Mom was holding her son. We talked about how she feels now. She is beginning to believe that her son will survive. She tells me that they are close to her family, especially her sister and nephew who is two an a half. "We haven't spoken to my inlaws for two and a half years. They don't even know that they have a grandson. This is their only grandchild. My husband's brothers and sisters do not speak to him.

COMMENT:

In conclusion, this was a very sad situation, which no doubt added to the father's depression. Further counseling was recommended. These parents decided against it, mainly because the father thought that it was unnecessary. In my opinion he needed help in working through his feelings about his parents, his depression and his guilt and sadness and anger toward them. I believe the small amount of counseling they did receive was beneficial in helping them accept their new son.

They took their son home three weeks after his birth.

8.4 VERY SMALL, SICK PREMATURE INFANT

First Meeting

History:

Premature male infant, 960 grams. Prognosis very poor. Father is a musician. Both parents have children from previous relationships. Mother has nine year old son who lives with his father and grandmother. Father has two year old son who lives with his monther.

I had met the mother in the nursery that A.M. I was standing by the isolette when she came in to see her baby for the first time. She appeared in shock. Numb. I introduced myself and asked her briefly how she felt. Then I left her to get acquanited with her son.

Meeting with Mr. and Mrs. Gardner

I asked them what their understanding of the situation was. Their reply was realistic. "The baby is very tiny. He does not have much chance of survival. We've decided to take one day at a time."

We talked about their feelings. I said, "I would guess that you are very scared." They both told me they were.

In the course of the discussion it became apparent that both parents were very willing to communicate to me and to each other. They were very interested in getting some help.

Mother told me that they had wanted the baby very much and had two operations to help her have this baby.

We discussed the importance of keeping communication open between them.

I asked them what they were feeling and they replied guilt, anger, frustration. Mother offered that she had spent three days at Arlington Hospital reviewing what she had done to cause the prematurity. "I kept asking myself, what could I have done differently."

I told her that this was a usual reaction. "Many parents wonder what they did. Some question diet, lifting, sexual habits or even 'bad' thoughts."

I asked them if they were sharing their feelings with one another. It turned out that Mrs. Gardner had talked a lot more about her feelings than had Mr. Gardner.

COMMENT:

Note this situation, which is typical. Many men hold back their feelings and try to take care of their wives during this type of crisis. They may feel that they must be the strong ones, that they must hold it all together, as related below. They may be afraid that if their wife is emotional--falls apart--that they are the only ones who can "hold it together." Sometimes both parents try to hold back their true feelings to "spare" their mate from what they think will be additional pain.

I asked Mr. Gardner why he had not discussed his feelings with his wife. He said he needed to be strong so that she could feel what she needed to feel. He said, "If she feels OK and I tell her I feel bad, then she'll feel bad, too." We discussed this for a while. I asked him, "What if she feels bad and you're feeling OK, would you want her to tell you how she feels?"

I asked Mrs. Gardner, "Do you want him to tell you how he feels, when he feels bad?"

"Yes," she answered, "I want to share his feelings with me, too."

"Maybe you two could make an agreement not to hold back your feelings from one another," I proposed. "This is a very tough time for both of you and you need each other now. We've found that sharing feelings, even crying together, makes people feel better, less isolated, less lonely."

They both agreed to try this.

Breast pumping instructions were given.

COMMENT:

All our premature babies are fed breast milk when they are able. Therefore, mothers are routinely given instructions to begin milk production. This enables them to do something physical for their baby at a time when they can do little else. Although it is very sad for a mother who is producing milk to have her child die, we feel that the positive benefits to the health of the infant and to the physical and emotional health of the mother outweigh any negative aspects.

Dr. Davitt then joined us to answer any medical questions that they might have. When asked, "How much chance does our baby have of survival?" she replied, "Less than a fifty-fifty chance."

COMMENT:

Because of the grave condition of their son, I moved more quickly with these parents than normally. We felt that we would not have very much time. As it turned out, I learned the next day that their child had died and they would not be back. We usually have parents come back in a few weeks for the autopsy report. This gives them a chance to ask questions and it gives us a chance to assess how they are doing emotionally.

These parents came for a follow up session after five weeks. They were assessed to be mourning and handling their lives and their relationship with each other normally for this stage in thier mourning process. There was nothing we could tell them about why the baby had come early. We could tell them that their child was normal in all other respects. We concentrated the session on their feelings and what they needed from one another and how best to get it.

CHAPTER 9
CONCLUSION

Parents of defective newborns have special needs which are not being met in most hospitals today. We know that these parents go through emotional trauma which can appear to be very changeable from one day to the next. We know that parents of defective children or parents who have a baby who dies have special problems with their relationship as a couple. These parents have a higher rate of separation and divorce than the average couple. Parents who are making life and death decisions about their infants face an agonizingly difficult task. The professional staff that is in contact with parents of defective newborns has a difficult task of its own.

We feel that parents need counseling as soon and as often as it is necessary. They need it from someone who has time and who is skilled in these matters. People who are interested in helping these parents should be identified among staff members and encouraged to get the skills necessary for this task. For example, a nurse who has worked in the Intensive Care Nursery and who is interested in developing counseling skills may be a good person for this job. The nurse may have to take courses in counseling or get help from the psychiatric department in order to gain the necessary skills. A social worker who is dedicated may also be a good choice, although a change in emphasis would be necessary for most social workers. Such a person would also need to learn medical details in order to speak intelligently on these issues. An already experienced counselor from any profession who could learn the medical details would be another good choice. Most physicians do not have the necessary time to devote to counseling although with experience, those who are interested become good part-time counselors.

The person selected must make this the primary job responsibility. When a defective infant is born, all systems must be ready to operate to help the parents deal with the crisis. We suggest, therefore, that major medical centers plan for a full-time specialist to do neonatal counseling. They must write this job into their budget as an essential part of running the neonatal department. For smaller hospitals, part-time help might be secured or someone from the existing staff could be trained and given responsibility for the counseling when a problem occurs.

We believe that staff members should be urged to communicate with each other about their thoughts and feelings on specific cases. Staff people must support each other at these difficult times. This can be encouraged by setting up meetings to air feelings and to share the difficulties which the entire staff has to deal with when taking care of very sick newborns and their families, or taking care of dying newborns, or going through the process of decision making about a sick infant.

Medical students must be exposed to information about counseling procedures, life and death decision making, ethical and moral considerations for decision making, and treating patients and their families in a wholistic manner. They also need to have the opportunity to explore their own feelings about all these emotionally laden subjects.

There are many questions that need further exploration, such as:

> Who is <u>best</u> suited to do the neonatal counseling job?
>
> How do we teach students humanistic skills along with the scientific skills they are acquiring?
>
> How will each individual hospital with its unique set-up and unique staff best handle parents of defective newborns and the problems they present?

A way to prevent long term problems, like the one below, must be found:

> It's been eight years since our baby died. I can hardly stand to think about it. There's a cloud over that period of my life that still hangs on and hasn't lifted yet. It was the most horrible thing that I could imagine. We didn't know what to do or say and no one helpd us. The doctor and the nurses avoided us like something was wrong with us or that they just couldn't stand being around us. I felt isolated as a person from my husband and from friends and relatives. When I also felt isolated from the staff in the hospital I really knew things were bad. I figured, if any-one could help it would be the staff members, who were used to being around sickness and death. When they didn't help, I gave up and just suffered alone.
>
> Now looking back, I think a lot of our problems could have been avoided if we had had some kind of counseling at the time of our baby's death.*

Personal interview with mother

APPENDIX A

AT THE FIRST MEETING, WHAT MIGHT WE SAY?

In our experience, parents have found it helpful to have time to talk, not only about the baby, but about their own feelings. During the time that your baby is in the nursery, we'll meet with you as often as necessary.

It is usually a big strain having a sick baby, so we'd like to help as much as we can. Any questions that you have, we'll try to answer. Any problems that come up, we'd like you to feel free to bring up with us. Of course, we'll keep you posted on the baby's condition. We want you to know everything so there will be no surprises.

The nursery is running all night long just as if it were daytime, so if you want to call in at 2:00 a.m., please do.

Anything can be discussed in our sessions. There are no limits.

APPENDIX B

SIX TO EIGHT WEEKS AFTER THE DEATH OF A CHILD, WHAT MIGHT WE SAY?

During the session, we seek answers to these kinds of questions:

1. How are you two feeling at this point?
2. Are there still times of sadness?
3. Are you expressing your feelings to one another?
4. Do either of you feel angry at this point?
5. What about the guilt that we talked about earlier?
6. How is the rest of your family doing? (other children, their parents, the grandparents, etc.)
7. Do you have any questions for us?
8. Have you thought whether or not to have another baby?
9. Have you thought about when?

COMMENT:

We discourage parents from even thinking about another baby for at least six months and to wait a year before conceiving again. We usually ecplain the reasons behind this at one of our last sessions. Basically, we want them to mourn the current child. It is important that they not replace the dead child with a new child before the mourning process is completed. This would be tragic for the new child, who then would not have his own individual identity, but in part be the "lost" dead child.

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ABSTRACT

COUNSELING PARENTS OF DEFECTIVE NEWBORNS is a primary data study and analysis of five years of direct experience with parents whose defective children were being cared for by the neonatal unit of Georgetown University Hospital in Washington, D.C. The counseling program used a flexible, process-oriented model that incorporated basic Freudian theories with the less traditional theories and methods of bioenergetic, gestalt and transactional analyses. This model was continually revised and expanded as we interacted with the parents, the hospital staff and two leading ethicists, Richard McCormick, sj, and John C. Fletcher, Ph.D. The core team was the neonatal counselor (author) and two neonatologists, Dr. David Abramson and Dr. Mary Kate Davitt. Included in our data are: actual case studies; interviews (five neonatologists, ten pediatricians, five residents, ten nurses and eight clergy); and the retrospective views of five sets of parents and two mothers concerning the counseling process they had been through with their defective newborns.

We found that, during this type of crisis, parents need special attention that is not being given because hospital personnel are trained to focus on the problems of the newborn and to deal only with the physical and medical aspects of the situation. Parents can be helped by one or more staff members who are trained in a wholistic approach to family health that includes emotional support for the mother, father, grandparents and siblings and concern for their individual and relational well-being. If the infant survives, the quality of that survival depends on whether or not

the family has dealt with the emotional issues involved in the birth and disability. If the infant does not survive, the health of the parents and existing or future siblings is promoted by the counseling process which we have pioneered and described in this monograph.

This counseling process is especially crucial when parents must make decisions about the care of their seriously ill babies. If both the intellectual and emotional aspects of any decision are fully explored with the aid of a trained counselor, parents can and, in fact, we believe should, make the medical decisions required by their particular crisis. In this respect, our conclusions run counter to the commonly held and practiced belief that tragedy stricken parents are incapable of making life and death medical decisions. We recommend that, in proportion to the number of defective neonates a hospital normally cares for every year, it should have full or part time staff personnel or consultants who are trained to support the parents and families through a wholistic counseling program.