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# Family Practice Grand Rounds

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## Neonatal Death: The Family Is The Patient

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Denver, Colorado

DR. ROBERT FRIED (*Chief Resident, Family Medicine*): In our Grand Rounds conference today, we will discuss the case of a newborn infant from our practice who died after a complicated neonatal course. The focus of our discussion will be more on the family as the patient and the family physician's role in high-risk obstetric and perinatal care than on the specific medical issues involved.

Participating in the discussion are Dr. Arlis Adolf, family medicine Fellow and this family's physician; Dr. Richard Patt, assistant clinical professor of family medicine; Dr. Eugene Farley, Chairman of the Department of Family Medicine; Dr. Linda Farley, Director of the family medicine center; Dr. Larry Green, Director of the residency program; Dr. Keith Lammers and Dr. Linda Burnham, third year residents; and Ms. Kathy Fenn, a pediatric nurse whom some of you know from the hospital. Special resources for us today are two trained pediatricians who are now family physicians, Dr. Steven Poole, who is assistant professor of family medicine and pediatrics here, and Dr. Arnold Greensher, the Director of the family medicine residency at the University of Arizona, who is visiting with us.

DR. ARLIS ADOLF (*Family Medicine Fellow*): In thinking over today's case, I can find no way to present it adequately without including a discussion of the entire family's involvement and need for care. First, let me give you some background information on this family. The mother is a 25-year-old primiparous patient who was the eldest of seven children in a strongly Catholic family. She has a master's degree in social work and

previously counseled patients on obstetrical and nursery floors, but for the last year, since moving here, she has been her husband's business manager. The father is a 30-year-old architect, primarily self-employed. He was an only child and had lost his own father only a few months earlier to death from a prolonged bout with throat cancer.

The family first presented to the Family Medicine Center in June 1978, at what was thought to be the eighth week of pregnancy. The mother initially had mixed emotions about this unplanned pregnancy, but with enthusiastic support from the father she was soon eagerly anticipating the arrival of her baby. The pregnancy was unremarkable until the estimated gestation of 29 weeks, when the patient developed vaginal spotting. With bed rest, the spotting stopped, but the patient noted decreased fetal movements. The following day, after sudden rupture of membranes, the couple came to the hospital, where contractions occurring every three to four minutes and a moderate amount of vaginal bleeding were noted. There were no signs by physical examination or portable ultrasound of placenta previa or an abruption, but fetal distress was noted on the external monitor tracing, leading to an emergency cesarean section. The amniotic fluid was grossly bloody and a blood clot diagnostic of abruptio placentae was found. The baby was a 1,430 gm male with Apgars of 1, 5, and 8 at one, five, and ten minutes, respectively. His resuscitation, including a traumatic intubation, was followed by stabilization and extubation, and then reintubation when he again became severely hypoxic. A chest x-ray revealed diffuse opacification of both lungs, consistent with poor ventilation and/or severe respiratory distress syndrome, as well as a moderately severe pneumomediastinum. In addition, he was noted to have an absent left ear canal, with a low set, markedly deformed left external ear, micrognathia, and a minor left facial

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deformity. Following a brief visit by his father in the nursery and by his mother at her bedside, he was transferred to a neonatal intensive care unit in another hospital.

Meanwhile, the mother developed postpartum preeclampsia with tremulousness, hyperreflexia, clonus, and elevated blood pressure. Because of concern for this condition, she was told only that the baby had a deformity of his ear, in addition to the respiratory difficulties we had anticipated. Though she did voice anxiety for the baby, her responses were blunted by pain, preeclampsia, and postoperative medications. Both patients' conditions were discussed in some detail with the father, who was understandably anxious and tearful. Following his request for medication to help calm him through the night, he was given diazepam which reportedly had no effect.

Further evaluation of the baby revealed esophageal atresia and a tracheo-esophageal (TE) fistula. Because of this defect, abdominal distention occurring with forced ventilation made the ventilation progressively less effective. Thus, the following morning a gastrostomy tube was placed to decompress the abdomen. However, the resulting air leak through the tube, with subsequent hypoxia, necessitated immediate thoracotomy and ligation of the TE fistula. The hypoxia improved until transfer to the recovery room, where the  $PO_2$  ranged from 18 to 36 mmHg for 1½ to 2 hours. There, on neurologic examination, the baby was noted to be even more flaccid than he had been since birth. Having earlier that morning informed the mother of the baby's anomalies and need for surgery, I returned to prepare her for the fact that he was doing poorly and might not survive the postoperative period. Our conversation led me to understand that for this couple, coping with a severely handicapped child, especially one which might be mentally handicapped, would be much more difficult than accepting the child's death. Fearing severe hypoxic brain damage, I called the anesthesiologist and the nursery resident to express my wish to be involved in future decisions regarding the institution of further heroic treatment. The baby improved somewhat, however, and instead I got a call from a neonatal Fellow who was concerned that I was giving up too soon on a child who had "totally reversible" conditions, and that perhaps I was not aware of how well many other babies do after a stormy course in a neonatal

unit. I reassured him of my agreement with their present plan of support for the baby, but reiterated my concern about severe neurologic damage. Throughout this first day, the father maintained frequent telephone contact, supporting the plan to do whatever was necessary.

The following day the baby's respiratory status remained poor but stable, despite clinical evidence of hypoxic insult to heart, lungs, and kidneys, and the recognition of a Patent Ductus Arteriosus (PDA). Neurologically, the baby showed slightly more spontaneous limb movement, but remained quite hypotonic. Most ominously, he had developed skin sclerema, which is a poor prognostic sign.

DR. ARNOLD GREENSHER (*Pediatrician and Family Physician, University of Arizona, Department of Family Medicine*): Yes, sclerema neonatorum is a generalized thickening of the skin associated with any of several problems such as hypoxia, as is probably the case here, sepsis, and prematurity. It usually indicates a very poor prognosis.

DR. ADOLF: The baby's condition and plans for treatment were again discussed with the nursery staff, with my stance remaining unchanged. In a long discussion with the parents, I described the baby's problems in detail, but tried to remain optimistic enough to allow some parent-child attachment. The mother, whose preeclampsia was now resolved after 24 hours of magnesium sulfate, was less medicated and more depressed. The father still was quite anxious and upset. They both ventilated their feelings well, including the guilt they felt regarding the mother's "sniffing" of a small amount of amphetamines in the first trimester, before she knew she was pregnant. My role was to offer empathy and support and to encourage the father to visit the baby, offering to accompany him, if that would make it easier. Both parents seemed more at ease at the end of this session.

However, on the fourth day, with no change in the baby's status, the mother was very depressed and tearful, voicing concern for the suffering she felt the baby was undergoing and expressing the feeling that it was unfair to prolong his life artificially when he had so many problems. At the same time, she felt guilty for wishing her baby would die. The father also began ventilating feelings of frustration, anger, and helplessness at not being

able to alter the treatment plan for his son, whom he also felt should be allowed to die. He mentioned frequently his grief over his own father's death, recalling similar frustrations at the agonizing prolongation of his father's life that he felt the medical community had imposed. Because of these strong feelings, he had been unable to bring himself to visit his son in the nursery.

I again empathized with the parents' feelings and informed them that I already had been advocating no further heroic treatment, but also felt that we needed to give the baby more of a chance to respond to medical treatment. In addition, my growing concern about the seeming lack of parental attachment led to the question, "What if the baby lives?" The mother was able to consider changes in their lives that would result, but the father could not accept that eventuality, especially if the baby were handicapped, requiring a major alteration of their life-style.

On the fifth day the nursery staff decided that since they had been unable to lower the ventilator settings, the PDA should be ligated. The neonatologist contacted me and I agreed to discuss this and the baby's general condition once more with the parents. However, when the father arrived it was immediately apparent that his mental state precluded any discussion of the baby. He was severely agitated and sometimes irrational, pacing the room, yelling, pounding his fist, and being occasionally quite hostile to me and his wife. Finally, he admitted drinking heavily the previous night, and had just rolled his truck and been arrested for driving under the influence of alcohol. After he was allowed to ventilate his anger as well as his emotional and physical pain, his wife was able to calm him somewhat, and he agreed to stay as a guest in the other bed in his wife's hospital room that night and allow us to take care of him. After any serious injuries were ruled out, he was given haloperidol and spent a quiet night.

The following morning, with their feelings more controlled, the parents agreed to accompany me to meet the neonatologist and visit their baby. The baby's condition remained the same, but the neonatologist now felt more uncomfortable about withholding the PDA surgery. He proposed, as a compromise, obtaining a Computerized Axial Tomography (CAT) scan to look for evidence of intracranial bleeding which would confirm significant neurologic damage. The mother spent a few

minutes with the baby, but the father still could not go into the nursery. Following that visit, not only did the parents decide to consent to surgery if the CAT scan were negative, but both parents also showed more attachment and hope, asking questions like "When will the baby be able to go home?" and "When will he catch up with other children in growth?" The mother expressed relief at seeing that the baby was not the "monster" that she had imagined, though it had been difficult to see him attached to numerous tubes, machines, and IVs.

The CAT scan showed intracranial hemorrhage bilaterally into caudate nuclei, subarachnoid spaces, and the ventricular system with resulting hydrocephalus. This was particularly difficult news to present to the parents, following their rising hopes of the previous day. Again they went with me to the hospital, where prior to another joint conference with them, the neonatologist and I agreed to assume the responsibility of discontinuing all the baby's support, rather than having the parents bear the burden of that decision, or having the baby suffer a prolonged hospitalization and death. After discussing the baby's prognosis and our recommendations, and getting the parents' agreement, the equipment was quickly withdrawn and the mother was allowed to hold her baby while he died, with the support of the baby's primary nurse. The father remained in the consultation room, where he began sobbing and ventilating to me his grief over the deaths of both his son and his father. Following the baby's death, both parents seemed sad, but relieved. Since that time I have had telephone contact with them and they seem to be grieving appropriately, slowing resuming their lives. Results of the autopsy are pending.

DR. STEVEN POOLE (*Assistant Professor of Family Medicine and Pediatrics*): I would like to mention one important and practical point here. After a couple has experienced the death of a newborn, as this couple has, there is an unexplained, but intense need by the mother to "see" her baby sometime within the following year. This is demonstrated by a visit to the grave or a need to see the urn containing the ashes. It is a universal phenomenon and seems to be part of the process of resolving her grief. This is something to remember when, as physicians, you are involved with a family who must make arrangements after a child has died. The family will also need further

opportunities to talk to the physician about the baby periodically during the next few years.

DR. FRIED: Dr. Patt has prepared some comments for us about the role of the family physician in dealing with the family and tertiary care specialists in such a case.

DR. RICHARD PATT (*Assistant Clinical Professor of Family Medicine*): This case represents one of the greatest challenges a family physician will encounter. Dr. Adolf was forced to deal with the very complex medical problems of a premature baby with multiple congenital anomalies, as well as a significantly preeclamptic mother. Simultaneously, the emotions of two distraught parents had to be controlled, and an attempt was made to nurture the integrity of the whole family, not knowing whether the baby would live or die.

Looking at the specific issues involved, the family physician must first arrange the transfer of the sick newborn to the tertiary care center, while attempting to minimize the psychological effects of this transfer on the parents. Next, contact must be maintained between the Newborn Intensive Care Unit (ICU) and the home, keeping parents as well as siblings aware of the baby's medical status. This can be done either by telephone or in person, depending on the proximity to the center. Where possible, I have found it especially worthwhile to arrange to meet the parents in the ICU during my visits. I am able to get a direct look at how they are relating to the infant and they are aware of my interactions with the baby, neonatologists, and staff. I think the family physician should also serve as a consultant to the neonatologists concerning the response of the family to the birth and subsequent illness of the newborn. The December 1977 issue of *The Journal of Family Practice* has an article addressing some of these facets of perinatal care.<sup>1</sup>

Many other problems will continue to develop out of this type of situation, as today's case clearly demonstrates. Postpartum depression, parental guilt, and pathological grieving are psychological issues which can be handled best by a family physician who has had previous, and will continue to have future, relationships with the family. The most difficult question to answer is what *should* be done for the child, as opposed to what *can* be done. This requires a tremendous amount of guidance from a family physician who understands the medical aspects of the problem and can integrate

this with the psychological make-up and status of the entire family unit. Another article which discusses some of the dilemmas faced in the nursery is in *The New England Journal of Medicine*.<sup>2</sup>

DR. EUGENE FARLEY (*Professor and Chairman, Department of Family Medicine*): Besides the difficult decisions and issues of grief and guilt, the anger and frustration that family members feel toward each other as well as toward the medical care system also need to be recognized and addressed. When the physician does attend to all these issues, a significant bonding and attachment forms between the patients and their doctor.

DR. KEITH LAMMERS (*Third year family practice resident*): I would like to discuss the bonding and attachment of these parents to their baby. It seems that was one of the harder things to deal with in this case.

DR. ADOLF: Yes, we often seemed to be imposing contradictory expectations on these parents. On one hand, they were encouraged to attach to and plan for the baby while on the other hand, to disengage themselves from him in preparation for his death.

MS. KATHY FENN (*Pediatric Nurse*): Attachment is very important, however. Remember Klaus and Kennel's book, stating that parents were better able to work through their grief after achieving some attachment with their baby, than they were if they had not been able to form those bonds.<sup>3</sup> And it is important that someone in the medical system, such as the primary care physician, takes time to facilitate and encourage bonding, because a high-risk nursery can be a busy and frightening place to parents.

DR. LARRY GREEN (*Assistant Professor of Family Medicine*): I want to know how you are doing, Arlis.

DR. ADOLF: Gradually getting better. I went home the afternoon after the baby died and had a long cry, which was therapeutic for me. But the emotional strain one undergoes in a case like this is an important issue to consider, to say nothing of the large time commitment involved.

DR. GREENSHER: That is very true. A physician who has to decide to turn off a respirator, especially in a nursery setting, goes through incredible feelings of guilt and sadness himself. This may haunt him for weeks or even months. That makes it very important for a physician to have his own support systems to lean on at

such times.

DR. LINDA FARLEY (*Family Physician*): Yes, that is important. Dealing with this kind of situation is one of the most difficult things to do in medicine. But it is exactly the kind of problem that the family physician can handle better than anyone else because of his knowledge of and relationship with all members of the family.

DR. FRIED: What about the problem of the time involvement of the physician in a case like this?

DR. EUGENE FARLEY: It is a major time investment that one makes. However, if the family's feelings and problems are not dealt with now, they are likely to show up later as prolonged depression, numerous somatic symptoms, frequent office visits, family disruption, or in other forms. Ultimately, this may take more of your time than the intense investment we are talking about in the acute situation.

DR. LINDA BURNHAM (*Third year family practice resident*): Another suggestion is that other professionals, such as nurses or social workers, can talk with these patients, thus relieving the physician of some of the time commitment.

DR. PATT: Time is only one of the factors that makes dealing with a problem like this so difficult. Besides time, the family physician must have an adequate fund of knowledge about current developments in neonatology. Keeping up with the latest diagnostic and therapeutic modalities is certainly a major challenge. The most difficult aspect of all, as was obvious in Dr. Adolf's presentation, is the mental effort and strain on the family physician. One could certainly wonder if this investment of time and one's self is worthwhile. However, when acute events are over, this family, with or without the new baby, will still be patients of their family physician. When a physician goes through a period of maximal stress like this with a family, he develops an understanding of them, as well as a relationship with them, that is unequalled by any in his practice. This is the type of reward that makes all of the effort *completely* worthwhile.

DR. ADOLF: That is really true. Besides the rewards of a close relationship with that family, one also undergoes a lot of personal growth in the process.

There are many things to learn from this case, but I would like to summarize a few of the more outstanding points. The physician needs to re-

member and concern himself with the significant effect that illness in one member of the family can have on others in that family. As researchers have demonstrated and most parents will testify, fairly strong attachment to their baby develops in parents, especially mothers, even before birth. This means that when the baby dies, it usually is as significant a loss to them as if another family member had died. Family and friends frequently do not realize this and may act as if the loss of the baby is not a big event. This approach is sensed by grieving parents as a lack of support<sup>4</sup>; it may be prevented by an alert family physician who can talk with the family. It also is important for the parents to see and, if possible, touch or hold their baby before or even after death. This is especially important if the baby has anomalies, so that the parent can see the normal as well as the abnormal features of their baby. When deprived of this opportunity, parents feel a sense that the baby was not real, and have a difficult time working through their grief, as well as loss of confidence in their ability to have a normal baby.

These parents are often surprised themselves at the intensity of their grief which may be manifest as (1) somatic distress, (2) preoccupation with the image of the deceased, (3) guilt, (4) hostile reactions, and (5) loss of the usual patterns of conduct. As mentioned before, the hostile reactions may at times be directed at the medical system or doctors, especially if, as in this case, previous experience with the system affects the parents' perceptions of the problem. Because they may not be at the same point in their grief and thus feel misunderstood by their partner, parents may also become hostile towards each other. However, if helped to communicate their feelings together, each can become the other's greatest support.

Finally, it is important for a family physician to have his/her own support system to utilize, both when making life and death decisions, and also when he/she is grieving over the loss of a patient.

#### References

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