Family Practice Grand Rounds

Follow-Up Care of the Premature Infant: The Family Physician's Role

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DR. FRED CHU *(Third-year resident in family practice)*: There are 180,000 preterm infants born in the United States every year.[1,2] Many of these premature infants are critically ill and require several weeks and months of hospitalization. Neonatal care centers have developed sophisticated multidisciplinary teams to help deal with the medical and psychosocial problems involved in the care of premature infants and their families. After discharge the family physician often takes over as the primary source of medical care. In today's Grand Rounds, we hope to bring up issues that will help to close the gap between neonatal care centers and practicing family physicians and to offer suggestions regarding the follow-up of premature infants.

First, I would like to introduce Mrs. Ferguson, a parent of two premature babies. Mya, who is now 3 years old, was born at 32 weeks' gestation, and Mathew, who is 16 months old, was born at 30 weeks' gestation. Both had long, complicated hospital courses.

The first question I would like to raise is, What is the family physician's role in caring for the infant and family during the acute period while the infant is still in the neonatal intensive care unit?

DR. EDWARD GOLDSON *(Director, Newborn Follow-Up Program, Children's Hospital of Denver)*: The family physician should be involved from the beginning. The neonatologist obviously has the major expertise in managing the acutely sick small infant. However, if the family physician knows the family and has been involved with the family all along, his expertise is in knowing and relating to that family. He can be involved in delivering information to the family, helping them understand what is happening with their baby, and providing general support.

DR. STEVEN R. POOLE *(Assistant Professor of Family Practice and Pediatrics)*: Mrs. Ferguson, what do you think the family physician's role ought to be?

MRS. FERGUSON: I agree with Dr. Goldson. When Mya was in the hospital, I didn't see the family physician until I went home. After Mathew was born, while he was in the hospital he was seen by my family doctor, who knew what was going on and who could help me understand what the spe-

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cialists were doing. Most important, my family doctor knew me. He knew I always act like I'm doing fine even when I'm dying inside. He was able to tell when I needed reassurance or to ask questions.

With Mya, the doctor didn't see her in the hospital, so I didn't have a lot of confidence in him, and I was really worried about taking Mya to him after she had been released. I think it helps the parents make the change to having the baby at home if they know the doctor knows the baby very well. With Mathew, the family doctor saw him regularly while he was in the hospital, and even though Mathew's condition was more critical, I wasn't so scared when I took him home.

DR. POOLE: What sort of communication should go on between the neonatologist and the family physician during the child's intensive care stay?

DR. GOLDSON: Since the office-based physician is going to manage the patient over the long haul, the office-based physician should be apprised of everything that goes on. When the child is put on the ventilator, the family physician should know so that he will have a better perspective on the problems the infant had, what the parents went through, and what he will need to follow up on. He can interpret for the parents and be supportive.

MRS. FERGUSON: I know a lot of parents who complained of friction between the family physician and the neonatologist. They would get conflicting advice or opinions. Because there is so much confusion and tension in the families, and decisions have to be made, I think the friction was detrimental. It would be best if the doctors could work out their plan and then talk to us. It always helps, though, to hear it from our family doctor.

MS. MARGY STEWART *(Nurse Coordinator, Newborn Follow-Up Program, Children's Hospital of Denver)*: One major thing that upsets parents is the move from a level III intensive care nursery to a level I or II nursery in the community hospital, even though the hospital may be closer to home. I think the distress has to do with trust. The parents trusted the level III center that saved their baby. Suddenly their child is sent to a level II nursery, a place they don't know, and it makes them nervous. The family physician can be involved in that transition to create a more even level of trust for the parent.

DR. GOLDSON: This transition is difficult for parents, but with good handling it can work out well. Part of the responsibility lies with the neonatologist and the level III nursery and part with the family physician and the community nursery. The physicians and nursery staff can be talking with the family for days in advance, preparing them, describing the community nursery in a positive light. Perhaps a visit to the new nursery to look around and meet staff can be arranged. The family physician should see the child on the day of transfer and plan to meet with the parents.

MS. STEWART: Discharge from the hospital is also a difficult time for parents, a period in limbo. The parents leave all the care, help, support, and expertise offered by the hospital. It would be good to have the physician or some knowledgeable person available to provide continuity, to answer questions, or just to assure that somebody knows the parents and the child.

DR. POOLE: So it sounds like that last day of hospitalization may be frightening for the parents. What exactly should the family physician do on that day?

DR. GOLDSON: The family physician should know what's going on during the final week of hospitalization regarding the final discharge plans for equipment, various supportive services, and subspecialty follow-up, arranging final evaluations and education of the parents. For example, parents need to learn how to operate the home oxygen equipment several days before discharge. Everyone must anticipate problems ahead of time because there are always snags. The last day the parents should be able to walk in, celebrate, and say goodbye.

DR. POOLE: A telephone call the day after discharge is also helpful. The physician can get plenty of information on how the child is doing; and the call can be very reassuring for the parents. A number of questions come up for parents that first day at home, and getting them answered greatly reduces anxiety. How should the first visit be handled?

DR. GOLDSON: A lot of it depends on the baby. Generally, I like to see the baby within the first few days after discharge to get a sense of how the baby is doing. Then I see the infant every couple of weeks for six to eight weeks. If the parents are making the transition comfortably and the medical condition is under control, then I see the child

Table 1. Premature Infant Medical Follow-Up

1. Serial growth measurements: graph height, weight, and head circumference on charts by age, corrected for prematurity until 2 years of age. After 2 years, plot by chronologic age
2. Serial vital signs: heart rate, respiratory rate, retractions, color, circumoral cyanosis, blood pressure (dopler works well)
3. Serial nutrition history: content, quantity, rough assessment of adequacy of calories, fluids, vitamin and iron supplementation
4. Immunizations: given by chronologic age; if severe growth delay, use height or bone age
5. Record of illnesses and hospitalizations
6. Hematocrit and reticulocyte count every 2 to 4 weeks until stable and increasing, then every 6 months until 2 years of age
7. Serial assessment of development: Denver Developmental Screening Test or Prescreening Developmental Questionnaire at each well-child visit. If there are any abnormalities, solicit help from physical therapist or infant stimulation program
8. Assessments of visual response: visual following in early months, strabismus is abnormal after 4 months, ophthalmological evaluation at 3 months if birth weight less than 1,500 g
9. Auditory screening: check response to loud noise in office, audiogram (by audiologist with experience in testing infants) on all premature infants between 3 and 6 months and again within the next year
10. For infants with chronic lung disease: serial transcutaneous oxygen and carbon dioxide monitoring (if not available, then blood gases), chest x-ray examinations, electrocardiograms, watching for right ventricular hypertrophy

at monthly intervals until the child is stable and does not require any special equipment at home.

DR. CHU: I want to backtrack a little and ask whether family physicians should be involved in the follow-up care of premature infants? If so, what should their role be?

DR. GOLDSON: Well, in most of the country family physicians are involved in follow-up care of premature infants, and they should be if they feel prepared to handle it and if they feel comfortable.

DR. POOLE: I agree. If they feel comfortable, they should be the primary care physicians, which often means spending a little time educating themselves on the particular problems the infant has. It also means finding good consultants to be available (at least by telephone) to back them up. Given these circumstances, the family physician can coordinate consultations and general care, monitor the infant's status in regard to growth, development, and other problems, provide well-child care, handle most acute illness, help the parents adapt, and be the family physician.

DR. GOLDSON: I would agree.

DR. CHU: Well, then, what are the key medical issues the family physician needs to consider in the premature infant?

MS. STEWART: This handout (Table 1) lists ten areas we try to incorporate into the medical follow-up of premature infants. There are several points bearing special comment. First, it is important to monitor body growth of premature infants, correcting for their gestational age until two years of age, rather than comparing them with other children their own chronological age. It is also important to get respiratory rates on premature infants with bronchopulmonary dysplasia (chronic lung dis-

ease) and monitor oxygen needs by using the transcutaneous oxygen monitor. We find that the blood gases are often not very reliable indicators. I know that doing this can pose a problem, particularly if you are practicing in a small community in which there is no transcutaneous oxygen monitor. If one is available, it can be used to make decisions regarding changes in chronic oxygen needs.

We have found hypertension in several premature infants. Six premature infants this year, with diastolic blood pressures over 120 mmHg, have required medication for hypertension and we're recommending that physicians follow blood pressures on the premature infants, particularly those who have had difficult nursery courses. Use either doplers or the palpation method with an infant cuff.

DR. GOLDSON: We have found hearing losses in a number of children who passed the original screening in the nursery. A premature infant, therefore, should have a formal hearing test by a qualified audiologist at least twice in the first two years of life. We've also identified children with hearing loss that has worsened during the first year.

We also recommend the infants be examined by an ophthalmologist at 3 months of age, particularly if their birth weights were less than 1,500 g. Even if there are no signs of retrolental fibroplasia, the small infant is at risk for problems such as strabismus and poor visual acuity.

DR. POOLE: Morbidity is likely to be both most obvious and highly treatable in the area of development. There is considerable evidence that early detection of developmental delays and early intervention with physical therapy or infant stimulation programs definitely improve outcome.[2-6] Close monitoring of development is therefore crucial. The Prescreening Developmental Questionnaire is a 10-item questionnaire parents fill out at each well-child visit. It is probably the best standardized, easiest, most sensitive, and quickest way of monitoring development.[7] The questionnaire is adapted from the Denver Developmental Screening Test, which is probably the most accurate screening test.[8] Any infant showing developmental delays should receive a formal developmental evaluation. In addition, for the premature infant who has had a difficult course in the nursery, it would be wise to have a formal developmental evaluation between 3 and 6 months of age. This evaluation should be done by the local resource person with the greatest experience with infants: a child psychologist with experience in infant developmental testing, a developmental pediatrician, a physical therapist with an expertise with infants, or another resource.

DR. CHU: How about the family physician's role in acute illness, such as colds, fever, and bronchiolitis?

DR. POOLE: Again, preparation is important. The neonatologist and the family physician should anticipate these illnesses and discuss potential problems and how to handle them before the infant leaves the hospital, particularly for infants going home with residual lung problems, congenital heart disease, hydrocephalus, or other congenital defects. The family physician must get the neonatologist to provide information on what to monitor, what to check when the child gets ill, and how to handle common problems. The family physician also must identify a good, available resource to contact for advice regarding acute problems.

DR. CHU: What should the family physician know about the psychosocial issues, and what should he be doing?

DR. POOLE: Having a premature infant interrupts the normal stages of adaptation to parenthood.[9-11] With a full-term baby, parents have progressed through anticipation and preparation, and in the late weeks of pregnancy they really begin to feel a greater readiness. After delivery, they have a lot of time to become attached to their baby and develop a relationship. Premature delivery is premature for the parents, too. They may not feel ready psychologically, and the medical care interferes with the development of relationship. So, the parents will be anxious and feel ill-prepared and may have difficulty with relating to their child.

Parents expect a normal, full-term baby, and this normalcy is lost. As a result, to varying degrees they go through stages of grieving that loss: shock, denial, anger, and anxiety. Later they begin to accept what has happened. Initially parents may withdraw from the baby until it becomes clear the child will live; later they get back into the relationship with the infant and adapt to the infant's conditions and needs. All parents feel some guilt, and all have unasked questions about causes.

The family physician needs to understand and accept these phases and help the family understand

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and accept them. The treatment of parents should be adapted to that stage the parents are in. Empathy and support are more helpful in the early stages, whereas some practical suggestions and information may need to be postponed until acceptance, adaptation, and reorganization begins. For many premature infants, parents are in the adaptation phase by the time of discharge. More psychosocial intervention may be needed if parents are still in the denial, anger, or intense grief phases at discharge.

MS. STEWART: The physician can be very helpful by just giving the parents an opportunity to express their feelings about the difficult time in the nursery and the difficulty in caring for this baby. The physician can let them know that there is nothing wrong with them if they feel angry or helpless because their baby cries all the time or stays up all night because the nurses used to play with it at night. The family physician can offer ideas to help them handle some of those difficulties, but mainly his or her job is to let the parents know that they're OK.

MS. LYNNE ARONSON *(Social Worker, Newborn Follow-Up Program, Children's Hospital of Denver)*: Often parents feel extremely anxious or that they are not competent to care for their baby (which comes from watching the nursery personnel care for their baby for so long). The family physician can help the parent see this is normal. Another important issue is home oxygen. I think many parents have anxieties (and rightly so) about having a child attached to equipment (monitor or oxygen). It is important to listen, empathize, and let parents know that all parents get anxious or feel nervous.

DR. GOLDSON: We need to ask very specific questions such as, Do you have a babysitter? Have you gotten a chance to get out? Has the baby been fun to take care of? How is he sleeping? How do you feel about leaving him? How is the sibling reacting? How are you sleeping? There are many questions that address how parents feel about and perceive their child.

MRS. FERGUSON: When Mathew first went home on oxygen, he sometimes turned blue. I would get really anxious, and wanted to be reassured that he was OK. When I did call, I appreciated the nurses and doctors showing that they knew how I was feeling, and they would answer

my questions. With my first child, Mya, the doctor answered my questions OK, but I don't think he understood. When Dr. Chu answered my questions, I knew he understood my fears. It made a difference.

DR. GOLDSON: I think it's particularly important for physicians to set aside enough time to talk to the parents about these issues, particularly if the baby has had a long and difficult time in the hospital. A physician can't do this kind of listening in just ten minutes.

DR. POOLE: That's an excellent point. Setting aside extra time is important for another reason. A premature infant often has many problems on the problem list the physician must deal with, and there is little time left over for anticipatory guidance, which is the one thing parents need most. Consequently, the premature infant needs more time allotted for visits.

Another issue is parent-child interaction. The parents do not respond to the premature infant in the way they would if the child were born at term and had no problems, but they don't often talk about that. We can bring this issue out in the open and discuss it. We might say, "It would be tough for anybody to take care of this baby and treat him like a normal child in terms of discipline, expectations, handling crying, and so on. Let's talk about this at each visit, how you're doing, what it's like to deal with these issues."

DR. JOHN GORDON *(Second-year family practice resident)*: A very difficult area is how to deal with parents when there are problems. How do you tell them that they aren't handling discipline well, or, worse, that their child is not developing well?

MRS. FERGUSON: I think that for some of the long-term developmental problems that come up with premature infants, the parents already know before they are told; it is just a matter of accepting it when they are ready to. Specifically, Mathew has cerebral palsy. I knew from the beginning that there was something physically wrong with him, but it wasn't until he was nearly ready to come home that I wanted to talk about it or wanted to know specifically what we needed to do. I find that in the parent groups I belong to, most of the parents say this is true. It takes longer for some parents than it does for others to admit it or face it.

MS. STEWART: It's important to allow parents to go at their own speed. You seemed to be able to work through a lot of things pretty well. Some people are not able to do that, and I think in those cases we need to offer them more support, more time to talk.

DR. GORDON: There is another side to this problem, too. I have a patient whom I delivered at 29 weeks who had very low Apgar. I was concerned that he would have cerebral palsy. It was hard to convey to the parents that we didn't know what was going to happen, and in this particular case, there was no way we could predict how well he would develop. I felt we were able to say to the parents that we would watch their child carefully as he grew older and try to tell them exactly how he was doing. Only time would tell, and we would follow him closely.

MS. STEWART: That sounds like a good way of handling this problem because you're telling the mother that you're not sure, that you can understand her feelings, and that you will work with her.

DR. GOLDSON: I might mention that the more we look at the data for the premature infant, the Apgar is a very poor predictor of outcome. The Apgar score was originally designed for term babies, and Virginia Apgar has said that it was not meant for premature infants. It is extremely unlikely to find a 28-week infant with a 5-minute Apgar of 10. Furthermore, to make a prediction for 2 years of age on the basis of that Apgar doesn't make sense. We must recognize that in this group infants are phenomenally adaptable, so I say, "Let's see what they do over time." Of course, you must be constantly monitoring development and getting intervention if the child isn't up to his correct gestational age.

DR. POOLE: Let's switch for a second to another difficult issue—finances. The financial aspects of having a premature baby can be horrendous. What does the family physician need to know about finances, and what can we do to help?

MS. ARONSON: Finances can present a very difficult problem. There are, however, several potential resources.[12] The best person for the physician to contact is a social worker, who then can pursue the various resources. Many families are, of course, covered by insurance. Many poorer families are covered by Medicaid. The family hardest hit is the middle-income family without insurance. Some hospitals grade the charge on ability to pay. This usually does not help middle-income families. The Handicapped Children's

Program will pay for certain, specific handicaps if families are financially eligible. They will often pay for congenital defects and children with certain sequelae as a result of prematurity. There may be other local foundations with money available. In many states the local school district is responsible for providing special service even in infancy. Aid to Dependent Children may help with certain aspects of care. If your hospital does not have a social worker familiar with these resources, then contact the local Department of Child Welfare or the Department of Education.

Financial demands continue after discharge with such things as home oxygen, physical therapy, apnea monitors, ophthalmologists, infant stimulation programs, and so on.

DR. GOLDSON: If parents fall into the middle-income bracket they may get partial coverage. Different carriers will pay for different things. For instance, some carriers will pay for physical therapy, but won't pay for oxygen; other carriers will pay for equipment or any hardware involved, but will not pay for speech and language evaluation. It is important to find out about their coverage.

MS. STEWART: Also we often see cases of noncompliance, not because parents don't care about the baby, but because they can't afford treatment. So our role is not only to prescribe treatment but also to adapt the treatment to parents' finances and find someone to help with financial assistance.

MRS. FERGUSON: When I found out that Mathew needed therapy, I wanted him to go to Children's Hospital, but I couldn't afford it. We were really fortunate and had good insurance this time, so it wasn't as bad as it was with Mya. Still, therapy twice a week at $25 a visit, I couldn't swing it. I checked into different places and they referred me to the Cerebral Palsy Center in Denver. At first I was uncomfortable going there because I thought that if Mathew were at Children's, he would do much better. Then I realized that most therapy has to do with the parents' participation and how much effort they're willing to put into it. I think that should be stressed.

MS. STEWART: Did the name cerebral palsy make it difficult for you to go there?

MRS. FERGUSON: Yes, it did at first. I immediately called Dr. Goldson and Dr. Poole and said: "This says cerebral palsy. Does that mean that Mathew has cerebral palsy?" They had mentioned the term before, but I guess I didn't hear it, and I had trouble accepting it. But, after I was there awhile and listened to the therapist talk, I realized that it was Mathew, and *he* wasn't cerebral palsy, he *had* cerebral palsy; then I felt OK with it, then it didn't bother me so much.

DR. CHU: Are there other resources we should think of?

MS. ARONSON: Regardless of whether your patient needs assistance with financial problems or in finding appropriate evaluation or treatment, there are other resources. Visiting nurses (public health nurses or the Visiting Nurse Association) can be very helpful in identifying local resources. We have mentioned local social service and child welfare departments. The Department of Education may know of local therapeutic programs. The local community mental health program may know of resources. The United Way puts out a free booklet listing resources.

DR. POOLE: There is another issue we ought to cover, that is, the effect of having a premature infant on the family members and their relationships together. Any thoughts on this?

MS. ARONSON: As we have discussed, having a premature infant is quite a stress to parents and, therefore, a strain on the marital relationship. Parents often feel some guilt about the cause for prematurity. Parents may go through periods of significant depression. Oftentimes, the parents' methods of coping with this may be quite different; one may become very involved with the baby, the other may withdraw. One parent may blame the other. These problems and others make this a highly vulnerable time for the marital relationship. The family physician may be able to help parents recognize such problems and encourage more communication.

DR. POOLE: Siblings of any age will feel somewhat left out or relatively unappreciated if they are not made to feel a part of the care of the baby or if they don't receive special time with the parents. The family physician's first responsibility is prevention, by reminding the parents of the needs of the child at home and recommending that they try to spend play time with the children and take them to visit their premature sibling. When the infant gets home, the older brothers and sisters should be involved in the care of the baby to the greatest extent possible.

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It is also important for the family physician to recognize early symptoms in the sibling who is feeling a loss of parental attention. Some of the symptoms resulting from less attention or a high degree of family stress include discipline problems, bed wetting, hyperactivity, poor school performance, and other psychophysiologic symptoms. The most vulnerable ages are 6 months through 5 years, though youngsters of any age may be affected. The treatment usually involves more attention to the sibling in concert with consistent expectations and discipline.

DR. POOLE: One last question, Mrs. Ferguson. What do you wish that family physicians knew, or would do, that we haven't covered here?

MRS. FERGUSON: I was thinking about that yesterday. There are a couple of things. I think all mothers of premature infants think, "What did I do to cause this? Was it the time I drank too much, or the time I fell, or didn't eat right?" The physician has to anticipate these questions because the parent is usually too scared to ask. So ask us what we are wondering or what questions we have in the back of our minds. Give us credit. We know our baby pretty well. Listen to what we think. Don't just tell us what to do.

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