

A Family Medicine Approach to the Premature Infant

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Background: An increasing number of infants are born prematurely each year. Their care involves special needs and can include the active involvement of a family physician.

Methods: The MEDLINE database was searched for clinical reviews and original studies on primary care of the premature infant for the years of 1991-1996. Further sources included cross-references from these articles and standard textbooks.

Results and Conclusions: This article makes recommendations for inpatient care, discharge planning, and outpatient follow-up of premature infants and their families. The role of the family physician is emphasized. (J Am Board Fam Pract 1997;10:117-24.)

The birth of every child is a special moment. When an infant is born prematurely, the event is both exciting and frightening. Families are robbed of the final weeks and months typically used to make final preparations before the expected date of delivery. Simultaneously, the premature infant is thrust from the stable confines of the womb to the unnatural and abnormal surroundings of the intensive care unit. This article outlines the role of the family physician in the care of premature infants and their families.

Methods

The MEDLINE database was searched for clinical reviews and original studies on primary care of the premature infant for the years of 1991-1996, using the key words "prematurity," "primary care," and "neonatal intensive care unit." Further sources included cross-references from these articles and standard textbooks.

Background and Definitions

Prematurity is defined as any infant born before completion of the 37th week of gestation.¹ This definition encompasses a wide variety of newborns, ranging from 23-week-old infants at the edge of survival, to the relatively well 37-week-

old infants. Low-birth-weight infants weigh less than 2500 g. Approximately 3.6 percent of all babies born in the United States are considered to be low birth weight and premature. Very low birth weight infants, those weighing less than 1500 g, account for 0.8 percent of all live births in the United States.² Approximately 5 to 6 percent of all live births in the United States require intensive care, and most of these newborns (75 to 80 percent) are of low or very low birth weight.³ Almost all of these infants survive,^{4,5} and the great majority have normal outcomes.⁶

As an increasing number of premature infants survive, family physicians become more likely to care for these babies. Premature infants, especially those with bronchopulmonary dysplasia, are more vulnerable than term infants and are much more likely to be hospitalized in the first year of life.⁷ Premature infants are more susceptible to infectious diseases; sudden death; neurologic disorders; organically based behavior disorders; vision, hearing, and speech problems; and sociomedical complications.⁸ To deal with this wide range of problems, the family physician must also learn to deal appropriately with the physical, emotional, spiritual, and financial impact of the premature infant on the family unit.

Inpatient Management

Depending on the circumstances of the delivery, the initial role of the family physician in the care of the premature infant could be during the delivery itself. Starting with the critical moments be-

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fore delivery, the family physician must be prepared to act as obstetrician, neonatologist, counselor, mediator, social worker, and pediatrician. As soon as medically possible, the physician should ensure that the family is allowed to see and touch their new baby. To do so might mean wheeling the mother on a hospital bed to the neonatal intensive care unit (NICU) to see the newborn in an incubator on a ventilator. This brief moment may be the only proof to the family that the newborn really exists.

After the delivery the family physician can be involved on a medical basis, a social basis, or both. The importance of either role must not be overlooked. The baby might be born at or transferred to an institution where the physician does not have formal privileges. Every effort should be made to examine the infant shortly after birth in the presence of the family. Having the family physician simply handle the newborn can provide reassurance that the infant is indeed another member of the family.⁹ When holding the baby, it is helpful for the physician to point out how the infant is similar to a brother or sister. A comment about one of the baby's strengths or healthy features might long be remembered and appreciated.¹⁰

The family physician should continue to act as teacher and advocate throughout the infant's hospitalization. The physician should thoroughly explain in a simple manner the necessity of complex medical equipment such as the ventilator and phototherapy unit. Receiving such information from someone who has cared for the family for years, perhaps generations, makes the interventions easier to accept. In addition, the family physician might be called upon to convey bad news. Because the family physician has usually developed the greatest rapport with the family, it is appropriate that he or she serve in such difficult situations.

Much of the infant's early care will be provided by the neonatologist, and the family physician's major role will be in attending to the mental health of the family. Those families who receive emotional support during the infant's initial hospitalization, whether from a physician, social worker, or counselor, seem to have better long-term outcomes and are more comfortable as caretakers.¹¹ Initial fears center on the survival and intactness of the newborn.⁹ The family must be updated at least daily with consistent, honest, straightforward an-

swers regarding their infant's condition. Specific information about mortality and morbidity should reflect the most recent medical literature, not old, elevated mortality figures.¹⁰

Providing appropriate anticipatory guidance will help to prevent unnecessary worries. A good example is the issue of phototherapy. Phototherapy is almost always needed in premature infants. When the family is told this information in advance, they might feel reassured that their infant is similar to (not worse than) other infants. If phototherapy is not required, the parents can use it as a sign that the infant is doing better than expected. It is important to prepare the family for the reality of the newborn's effect on home life. Most families with premature infants at home experience months of heightened tension.¹² Assure families that increased marital discord is a normal and common means of dealing with the strain of the premature infant. Suggest to family members and spouses that they spend some time by themselves, and encourage them to maintain their own lives and interests.¹³

As an advocate for the family, the family physician should work with the nursing staff to encourage the family to participate in the day-to-day care of the newborn. In doing so, the physician can negotiate an acceptable care plan with the family and nursing staff. The guilt associated with the premature delivery is compounded every time a nurse performs the simple tasks the family knows they would be performing at home had the baby been full term. Empower the family by encouraging them to feed, bathe, and change the baby as soon as it is medically feasible.

The family physician should also help the mother decide whether to breast-feed. Discuss both the advantages and disadvantages of breast-feeding before the mother is discharged from the hospital. In certain situations the added task of breast-feeding and pumping breast milk eight to ten times per day could be too demanding emotionally. On the other hand, some women are empowered by their ability to provide the immunoglobulins for their infant that the physicians and nurses cannot. Be available to facilitate and support whatever decision the family makes, and be open to a change of heart.

A discussion of the ethical matters associated with severe prematurity and developmental disorders is beyond the scope of this article.

Screening Examinations

Ideally all appropriate screening tests are performed before discharge. The results of these tests will define areas of potential concern, dictate treatment, and guide follow-up care.

The following infants are at highest risk for retinopathy of prematurity: (1) infants born weighing less than 1300 g or at less than 30 weeks' gestation, and (2) infants born weighing less than 1800 g or at less than 35 weeks' gestation who received oxygen supplementation. These high-risk infants should have an ophthalmologic examination, including indirect ophthalmoscopy, by 5 to 7 weeks' postnatal age, either as an inpatient or outpatient, to detect retinopathy of prematurity.¹⁴ Current recommendations call for universal screening of all newborns, regardless of gestational age, with a brainstem auditory evoked potential to detect hearing problems. Table 1 lists those infants at highest risk for auditory problems.¹⁵

All infants born at less than 35 weeks' gestation and any infant with clinical symptoms of apnea or bradycardia should have an event recording (pneumogram or thermistor reading). All premature infants born at less than 32 weeks' gestation or born weighing less than 1500 g and any infant at high risk for interventricular hemorrhage should have a screening head sonogram. The sonogram should be performed in the first 4 to 7 days of life, and repeated near the time of discharge for those infants whose results were abnormal.¹⁶ Sonograms might need to be repeated at more frequent intervals if the findings are abnormal, depending on the severity.

Routine state-mandated newborn screening tests should be done at birth, and the thyroxine or thyroid-stimulating hormone measurements should be repeated at term. A complete blood count with a reticulocyte count should be obtained on all infants just before discharge, regardless of birth weight. Calcium, alkaline phosphatase, and phosphorous levels should also be measured for all premature infants at risk for rickets, which includes those whose birth weight is less than 1000 g or those with any gastrointestinal problems, a history of long-term total parenteral nutrition, and cholestatic liver disease.¹⁷ Any infant with abnormal findings on a chest radiograph and those with ongoing respiratory tract disease should have a chest radiograph before discharge.

Table 1. Newborns at Highest Risk for Auditory Disease.

Apgar scores of 0 to 4 at 1 min or 0 to 6 at 5 min
Bacterial meningitis
Birth weight less than 1500 g
Craniofacial abnormalities, including those with morphologic abnormalities of the pinna and ear canal
Family history of hereditary childhood sensorineural hearing loss
Hyperbilirubinemia at a serum level requiring exchange transfusion
In utero infection, such as cytomegalovirus, rubella, syphilis, herpes, and toxoplasmosis
Mechanical ventilation lasting 5 days or longer
Ototoxic medications, including but not limited to the aminoglycosides, used in multiple courses or in combination with loop diuretics
Stigmata or other findings associated with a syndrome known to include a sensorineural or conductive hearing loss ¹⁵

Drug levels should be obtained on all infants being discharged who are taking the following medications: theophylline, caffeine, phenobarbital, and vitamin E. All infants with chronic lung disease and heart problems should have an electrocardiogram and all infants born weighing less than 1000 g and those receiving furosemide therapy should have a dipstick urinalysis.¹⁷

Apnea Monitoring and Treatment

A decision regarding the use of an apnea monitor and medications should be made before the infant is discharged. Controversy surrounds the use of home monitors, as there is no test to screen for sudden infant death syndrome (SIDS), and there are no controlled trials supporting the use of apnea monitors to prevent SIDS.¹⁸ The following suggestions have been made regarding home monitoring:

1. Infants born at less than 34 weeks' gestation
2. Marked apnea documented after birth and not associated with reversible illness.
3. An infant whose sibling died of SIDS
4. Bronchopulmonary dysplasia or interventricular hemorrhage⁴

In addition, the American Academy of Pediatrics recommends that all premature infants be monitored for apnea and bradycardia in their car seats before discharge to single out infants at risk for apnea associated with car seat use.¹⁹ The physician should assure the family that many infants are discharged home on apnea monitors.¹⁸ Some families will welcome the monitor as a means of constant reassurance that their infant is well.

Families should be comfortable with proper use of the monitor as well as cardiopulmonary resuscitation before discharge.

Typically apnea monitoring is continued until the infant is free of symptomatic apnea for 2 months and free of apnea requiring stimulation for 3 months.⁴ If the infant has stopped taking theophylline or caffeine and has been apnea-free for 2 months, an event recording should be obtained. If the recording is negative, the monitor may be discontinued. If the infant is on a methylxanthine, the medication should be discontinued 4 days before the event recording. If the recording is negative, the monitor should be continued for an additional month and then discontinued if a repeated event recording is negative. If the initial event recording is positive, the infant could require further therapy with a methylxanthine.²⁰

Methylxanthines, such as theophylline and caffeine, may be used instead of or in addition to home monitors. Premature infants with episodes of central apnea lasting longer than 15 seconds and occurring more than three times in 6 hours, those with excessive short apneic episodes accompanied by bradycardia, and those with periodic breathing occurring in more than 10 percent of sleep time are candidates for medication with methylxanthines.²¹ Theophylline is easy to obtain at most pharmacies, and drug levels are easily measured, but theophylline is dosed on a two- to four-times-a-day schedule and has a high incidence of side effects. Caffeine is harder to obtain, and drug levels are less commonly measured, but caffeine requires only once daily dosing and has fewer side effects.

The theophylline loading dose is 4 to 6 mg/kg followed by a maintenance dosing of 1 to 2 mg/kg every 8 hours. The caffeine loading dose is 10 mg/kg, followed by 2.5 mg/kg once a day. Drug levels and their corresponding clinical response should be used further to modify daily dosing. Theophylline is usually therapeutic at serum levels of 5 to 10 µg/kg, and caffeine is generally therapeutic at 8 to 20 µg/kg.²² If possible, discontinue methylxanthines and any other unnecessary medications before discharge. No medications should be started on the day of discharge. Write out all prescriptions before discharge and have the parents fill these at an appropriate local pharmacy. The pharmacy might need several days to

obtain certain medications, such as caffeine preparations.¹⁷

Discharge Planning

Discharge from the NICU is stressful and exciting for the family as well as the medical staff. The infant might be discharged to a step-down nursery, a long-term care facility, or home. Although this change marks the end of a newborn's life in the NICU, it by no means signifies a resolution of the infant's medical problems.⁹ The family physician can do much to make the transition out of the NICU a smooth one.

A discharge meeting should take place approximately 7 to 10 days before the anticipated discharge. The discharge planning team should include the family, the family physician, the infant's primary nurse, a social worker and, if appropriate, a home medical equipment representative.¹⁷ The discharge meeting is particularly important to the family physician who did not have formal admitting privileges at the infant's medical center. The meeting also gives the family a chance to ask their infant's medical team whatever questions they need answered. Final teaching topics can be decided upon and skills subsequently learned before discharge.

The following community resources, as appropriate, should be contacted during the discharge planning stage to maximize care of the infant and family: social service agencies, home equipment companies, private-duty nursing agencies, mental health professionals, funding services, temporary housing, and community emergency services.¹⁷ Support groups exist for virtually all children with special needs, such as Parents of Premature and High-Risk Infants. Establish required subspecialty follow-up plans and, if possible, make all these appointments on the same day. If appropriate, arrange special transportation for discharge home and for all follow-up care.

Criteria for discharge vary from institution to institution and most have no strict definition. General guidelines include the following:

1. The infant is taking all foods by mouth and consistently gaining at least 20 to 30 g/d
2. Weight is approximately 2.0 kg or more
3. The infant's medical conditions are stable
4. The infant is able to maintain body temperature in an open crib
5. The family is comfortable providing for the

infant's routine daily care, is able to administer required medications and treatments, and is emotionally stable

6. Discharge planning is complete^{9,15,17}

Just before discharge the family physician should meet with the family to discuss their fears and answer questions regarding taking the child home. The physician should ensure that the nursing staff has completed teaching routine care of the infant. A good way to reduce parental anxiety is to have them stay in the hospital overnight with their infant for a couple days before discharge. Rooming-in will allow for them to provide 24-hour care for the infant while having the security of the NICU staff as backup. Reassure the family that they are not alone once the child is discharged. Give the family a written outline of pertinent telephone numbers, such as the NICU, the emergency department, and the clinic answering service.

Outpatient Follow-Up

Outpatient follow-up activities will obviously make up the bulk of the family physician's care of the premature infant. For many reasons outpatient care of the premature infant is not a simple series of well-child examinations. Premature infants and their families have many additional challenges, require more time, and need a more thorough review of ongoing medical problems at each visit.

Outpatient follow-up care of the family can start before the infant's discharge from the hospital. Ongoing parental and family support is of utmost importance. Encourage the family to take time for privacy, and assist them in arranging a schedule to normalize their daily routine. Empower the family through education. The first and most important teaching point is to explain corrected age. Subtract the number of weeks the infant was premature from the actual age to obtain the corrected age. Understanding this simple concept will alleviate parents' fears and decrease anxiety about child development.

Provide anticipatory guidance regarding such matters as sleeping, eating, and crying. Premature infants require more sleep than do term infants, but they also have a more rapid sleep-wake cycle. Their sleep-wake cycle might not normalize until they reach 3 to 4 months corrected age. Warn parents that the infant might not sleep 8 hours straight until he or she is 6 to 8 months corrected

age. Premature infants require more frequent feedings, even though their total intake can be less than a term infant's. Crying typically peaks at 3 to 4 months corrected age.²

The first office visit should occur no longer than 1 week after discharge from the hospital. Review a typical day with the family, and be aware of problem areas and ways to ease the transition. Early on, the infant should visit the physician as often as every 1 to 2 weeks to ensure adequate monitoring of weight gain and to provide rapid feedback and adaptation to problems.⁴ After the initial few months, when all medical conditions stabilize, the infant may be seen on a normal well-child schedule.

Growth should be monitored using growth charts for premature infants until 2 to 2 1/2 years corrected age.^{4,20} Premature infants will generally display catch-up growth for the first 2 years of life, especially around the corrected date of birth. Weight tends to catch up faster than height. Head circumference will be dramatically accelerated in the first 3 months corrected age until 6 to 8 months corrected age.² Future evaluation should be considered in the following situations:

1. The infant has not reached the 5th percentile of the full-term infant growth curve by 1 year of corrected age
2. Head circumference levels off at 6 months
3. No growth spurts occur by 1 year corrected age
4. The head circumference growth lags behind height and weight or is increasing at greater than 1.75 cm/wk
5. The infant begins to lose weight, especially if it loses more than 10 percent of body weight after discharge.²³

Every visit should include a discussion of the infant's nutritional intake. Most healthy preterm infants require approximately 105 to 130 kcal/kg/d for adequate growth. These requirements can be as high as 200 kcal/kg/d for infants with such conditions as bronchopulmonary dysplasia.²⁰ These calories can be obtained from breast milk, from commercial 20-kcal/oz formula, or from one of the special 22-, 24- or 27-kcal/oz formulas. Soy-based formulas should be avoided in premature infants until the infant's weight has reached the 50th percentile for corrected age. If the infant is breast-fed (20 kcal/oz), calculate whether human milk fortifier is necessary. The

fortifier makes the calorie load of breast milk comparable to that of special care formulas.²² Make sure all hypercaloric formula is mixed properly. Base all changes in formula and human milk fortifier use on the infant's daily caloric needs according to the growth curve. An infant on hypercaloric formula or human milk fortifier can be switched to standard cow's milk formula, soy-based formula, or breast milk alone when the following criteria are met: (1) the approximate total ounces consumed per day multiplied by 20 kcal/oz provides 100 kcal/kg/d or more, and (2) the infant weighs 2000 g or is at the 50th percentile for corrected age.²¹ Solid food should be initiated at 4 to 6 months corrected age.⁴ At 12 months corrected age the infant can be switched to whole milk.

In addition to increased caloric needs, premature infants also require supplemental vitamin A, B, C, D, E, and K, as well as iron, folate, and fluoride, during the first year of life. Vitamin K is usually administered by an intramuscular injection at birth, as it is given to full-term infants. Special-care formula will provide for most of the other requirements except fluoride and iron. Special attention must be paid to the iron content of these formulas. The third trimester accounts for almost all iron stores, and premature infants fail to receive some or all of this iron. Starting at 2 weeks of postnatal age, premature infants should receive 2 to 6 mg/kg/d of iron, either through iron-fortified formula or iron supplements.⁴ Most iron-fortified formulas contain 12 mg of iron per liter, whereas most special care formulas contain from 1.5 to 3.0 mg/L. For that reason, nearly all premature infants taking special-care (22-, 24-, or 27-kcal/oz) formula require supplemental iron to receive the desired 2 to 6 mg/kg/d.

All premature infants should receive a multivitamin supplement that contains 50 µg of folic acid until they are able to take 32 ounces of formula a day.²¹ All infants need 0.25 mg of supplemental fluoride per day if it is not available in the water source. All breast-fed infants should receive a daily multivitamin with iron for the first year of life. In addition, breast-fed infants should receive a supplement of 0.25 mg of fluoride and 50 µg of folic acid per day.^{23,24}

Anemia occurs in practically all premature infants. The most common form is iron-deficiency anemia, because of the lack of third trimester iron

storage and increased demands caused by rapid growth. Infants' hematocrits should be checked monthly until 6 months of age. The nadir commonly occurs at 6 to 8 weeks postnatal age, when it reaches approximately 7.2 mg/dL.²⁵

Follow-up auditory testing is dictated by risk factors (Table 1). Any infant with an abnormal brainstem auditory evoked potential response should have the test repeated at 6 months and the results referred to an audiologist.²⁶ Infants who passed screening evaluations or did not warrant an initial screening test should be monitored clinically for signs of impaired hearing or speech development. If appropriate, they should then be referred to an audiologist. A formal audiology evaluation is warranted for any infant who does not turn toward a sound by 6 months of corrected age and any infant whose verbal output decreases between 6 and 9 months of corrected age.⁴ When following up on hearing and speech development, particular attention should be paid to the concerns of the parents or family.

Premature infants are at risk for retinopathy of prematurity, strabismus, and other ocular problems. Monitor the infant at each visit for clear fixation and response to visual cues. Normally strabismus will disappear by 4 months corrected age,⁴ while clear fixation and following should occur by 6 weeks corrected age.²⁷ Any positive findings on ophthalmologic examinations should be followed up appropriately by an ophthalmologist. All premature infants should have a formal ophthalmologic evaluation for strabismus at 2 to 3 years of age.

The corrected age is typically used to track development during the first 2 to 2 1/2 years.⁴ Developmental surveillance scales allow for objective observation and documentation of the infant's progress as well as for early anticipatory guidance. The goal is not to predict later intelligence, but to pick up on any developmental delay and initiate proper interventions.²⁰ Development should be monitored starting at 0 to 3 months corrected age, using a formal test, such as the Denver Developmental Screening Test (DDST). There is much debate regarding the best developmental screening test for premature infants, but the DDST remains the most widely used.

All premature infants should grasp and roll from side to side at 6 months corrected age. They should transfer objects and secure a dangling ring

by 9 months corrected age and crawl by 1 year corrected age.²⁸ Monitor premature infants for asymmetry of tone and reflexes to detect hemiplegia syndromes. The most common pattern of early cerebral palsy consists of head lag persisting after 6 months corrected age, marked fisting, increased extensor tone of the trunk and legs, and increased flexor tone of the arms.²⁸ Many transient neuromuscular abnormalities will occur around 6 months corrected age and typically resolve by 18 months corrected age. Those abnormalities persisting beyond 18 months corrected age are cause for concern.

Immunizations should be given in the usual dose and dosing schedule according to chronologic, not corrected age.^{2,4,20} All premature infants should have received their first hepatitis B vaccine before discharge. If the infant remains hospitalized for 2 months or longer, the first diphtheria-pertussis-tetanus and hepatitis B vaccines should be administered in the hospital. Because the oral poliovirus vaccine (OPV) is live, it is not administered in the inpatient setting. A catch-up OPV might be required at the first office visit if it was not given as the infant left the hospital. Infants older than 6 months corrected age with chronic lung disease, symptomatic heart disease, or hemoglobinopathies, and those who are immunosuppressed should receive the split-virus influenza vaccine between October and December. The split-virus vaccine is given as 0.25 mL for infants between 6 and 35 months and 0.5 mL for those 3 years and older.²⁰

Conclusion

Family physicians will be called upon to provide care for increasing numbers of premature infants and their families. The tools required for such a task change as rapidly as does the technology. Ultimately, it is the human touch and hours of patient listening that will be remembered in the minds and hearts of the families.

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