

AMERICAN ACADEMY OF PEDIATRICS

Committee on Fetus and Newborn

Hospital Discharge of the High-Risk Neonate—Proposed Guidelines

ABSTRACT. This policy statement is the first formal statement of the American Academy of Pediatrics on the issue of hospital discharge of the high-risk neonate. It has been developed, to the extent possible, on the basis of published, scientifically derived information. Four categories of high risk are identified: 1) the preterm infant, 2) the infant who requires technological support, 3) the infant primarily at risk because of family issues, and 4) the infant whose irreversible condition will result in an early death. The unique home care issues for each are reviewed within a common framework. Recommendations are given for four areas of readiness for hospital discharge: infant, home care planning, family and home environment, and the community and health care system. The need for individualized planning and physician judgment is emphasized.

ABBREVIATION. VLBW, very low birth weight.

The decision about timing of hospital discharge of an infant after neonatal intensive care is complex. It is made even more difficult because of cost-containment issues and rigid definitions of medical necessity as determining influences on the length of hospitalization. Because of the pressure to discharge high-risk neonates at the earliest possible opportunity, it is important that guidelines are based on a review and analysis of current evidence. Shortening the length of a hospital stay may benefit the infant and family because decreasing the period of separation from the parents may lessen the subsequent adverse effect on parenting.^{1,2} The risks for hospital-acquired morbidity may be reduced.³⁻⁶ However, the overriding concern is that infants may be placed at risk for increased mortality and morbidity related to discharge before physiologic stability is established. Multiple investigators have found that preterm low birth weight infants who required neonatal intensive care experience a much higher rate of hospital readmission and death during the first year after birth compared with appropriate for gestational age, healthy term infants.⁷⁻¹³ Adequate time for preparation of the family to provide care in a home setting and for mobilization of community resources to provide support services is necessary before discharge. With advances in neonatal intensive care and changes in the economic and societal forces, the complexity of posthospital care issues has increased. A

single set of criteria for discharge readiness is no longer adequate. These guidelines, therefore, address four broad categories of high-risk situations: 1) the preterm infant, 2) the infant who requires technological support, 3) the infant primarily at risk because of family issues, and 4) the infant whose irreversible condition will result in an early death.

REVIEW OF THE LITERATURE

The Preterm Infant

The traditional approach to determining discharge readiness was the achievement of a preset weight, historically 5 or 5½ lb. During the past three decades several observational,¹⁴⁻¹⁷ nonrandomized,¹⁸⁻²¹ and randomized, controlled²²⁻²⁴ studies have been published that analyzed outcomes of preterm infants who were discharged after certain criteria were met. Although the population characteristics, the nature and results of the outcome measures, and the content of the early discharge programs varied, the common elements included:

- A sustained pattern of weight gain rather than a specific achieved weight,
- Physiologic stability defined as the ability to suckle feed and maintain normal body temperature in an open environment,
- An active program of parental involvement and preparation for posthospital care,
- Predischarge on-site home assessment,
- An active program of parental support after discharge of the very low birth weight (VLBW) infant,
- Frequent outpatient follow-up to assure adequate weight gain for the smallest infants in the weeks immediately after discharge,
- An organized program of postdischarge tracking and surveillance.

The safety of discharge after a shorter than usual hospital stay was supported by adequacy of weight gain and no increase in the number of acute care visits, unscheduled hospital readmissions, or early infant deaths in randomized studies with matched control cohorts. Each of these study designs included a program of parent education and infant follow-up.²²⁻²⁴ In the studies that addressed cost savings specifically,^{19,20,22,23} effectiveness was documented even with the inclusion of costs for coordination of care and services, home visiting, transportation, sibling care, and in-home support for the family, although in no single study were all of the aforementioned ancillary services provided. The success of the early discharge programs that incorporated special-

The recommendations in this statement do not indicate an exclusive course of treatment or serve as a standard of medical care. Variations, taking into account individual circumstances, may be appropriate.

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ized home care and follow-up surveillance indicates that the care required by the preterm infant and the support needed by families exceed that after discharge at a later postnatal age.

The three physiologic competencies that are generally recognized as essential before hospital discharge are the ability to maintain a normal body temperature fully clothed in an open bed with normal ambient temperature, the ability to coordinate suckle feeding, swallowing, and breathing while ingesting an adequate volume of feeding, and the ability to grow at an acceptable rate. These competencies are achieved by most preterm infants between 34 and 36 weeks postmenstrual age. Equally essential is the ability to maintain stable cardiorespiratory function. Data about maturation of breathing control and feeding behavior are more direct,²⁵⁻³⁸ whereas the maturational timing of the ability to maintain body temperature can only be inferred.³⁹⁻⁴¹ Although interrelated, not all competencies are achieved at the same postnatal age in a given infant. The pace of maturation is further influenced by the birth weight, the gestational age at birth, and the degree and chronicity of neonatal illnesses.

For infants with delayed maturation of respiratory control, use of home cardiorespiratory monitoring has been reported.⁴²⁻⁴⁴ The National Institutes of Health Consensus Development Conference⁴⁵ and the Canadian Pediatric Society policy statement⁴⁶ included prematurity with unresolved apnea as a potential indication for home monitoring. The success of home monitoring for unresolved apnea in reducing hospital stay without undue family stress has been observed.^{43,44} However, infant deaths associated with the lack of proper monitor use have been reported.⁴⁷ The pre-discharge clinical course and abnormal cardiorespiratory polygraphic findings have not correlated with subsequent alarm events requiring parental intervention⁴² and apnea of prematurity and risk of sudden infant death syndrome.⁴⁵ Thus, the decision to use home cardiorespiratory monitoring and pre-discharge polygraphic studies of cardiorespiratory function remains a matter of individual clinical judgment.

The Infant With Special Health Care Needs or the Technology-dependent Infant

In the past two decades, increasing numbers of children with unresolved and/or special health care needs have been discharged to home care with varying requirements for technologic dependence and/or support.⁴⁸ For newborn infants, the three broad groupings or categories of special care requirements are as follows: 1) those requiring special or assistive feeding techniques, 2) those requiring respiratory assistance, and 3) those with complex congenital anomalies requiring supportive and assistive devices. Only the first two categories are addressed because the population of the third group is very diverse and to our knowledge no data from controlled studies of home care have been published.

Gavage feeding as the primary mode of enteral feeding of sick and premature infants is a common practice in the hospital setting. There is no reported clinical experience of its use in home care of young

infants from which conclusions about safety, efficacy, and clinical appropriateness can be reached. Another approach for infants requiring long-term assistive feeding is placement of a gastrostomy; however, no clinical series of newborns with long-term home gastrostomy feeding has been reported. In the only reported series of home intravenous nutritional support of infants,⁴⁹ one death from catheter-related sepsis was noted. Somatic growth was maintained at normal rates, and six of the eight infants had normal developmental progress.

Infants with tracheostomies placed for various airway abnormalities have been cared for at home in recent years.⁵⁰⁻⁵² The underlying reason for the tracheostomy is reported to be the most important factor affecting the outcome, although airway accidents have been a major factor in adverse morbidity.

To date, no clinical trials have been reported that compare outcomes of home oxygen therapy in infants with bronchopulmonary dysplasia with those after prolonged hospitalization. Multiple observational studies have been conducted, however,⁵³⁻⁵⁵ the more recent of which have noted relative safety, ease of implementation, and cost-effectiveness.⁵⁶⁻⁵⁸ Prolonged oxygen supplementation is further supported by reported observations about its role in limiting progression to cor pulmonale,⁵⁹ facilitating normal growth rates,^{60,61} and avoiding unrecognized hypoxic episodes.^{62,63}

Reports of home ventilatory support of infants with chronic respiratory failure^{64,65} emphasize the need for continuous cardiorespiratory monitoring, disconnect alarms for mechanical support devices, and qualified personnel to provide bedside care to reduce the risk of death from airway accidents. Maintaining safe and adequate care is complex, emotionally demanding, and consumes the time and resources of families.^{46,65}

The Infant at Risk Because of Family Issues

Preterm birth and prolonged hospitalization were first reported as risk factors for subsequent child abuse in 1971.⁶⁶ In subsequent studies,^{67,68} infant risk factors found to be significant were VLBW, prolonged hospital stay, and congenital defects. Maternal factors included lower educational level, lack of social support, marital instability, and fewer prenatal care visits. Significantly fewer family visits during the stay in the neonatal intensive care unit had occurred for infants in whom subsequent maltreatment was documented.⁶⁷

The increase in substance use among the child-bearing age group has created a large population of children at risk for a variety of adverse medical and psychosocial outcomes.⁶⁹ Sequelae such as attachment disturbances, behavioral and developmental disorders, and child maltreatment have been observed frequently among children born to substance abusers.⁷⁰⁻⁷² Strategies to reduce the risks of adverse outcomes in infants at high risk because of psychosocial concerns that have been adequately studied have focused primarily on home visitation with or without additional social support services.⁷³⁻⁷⁹ The likelihood of success increased when an intervention

program for maternal substance abuse included addiction treatment for the parents.⁸⁰

The Infant With Anticipated Early Death

The concept of hospice care for neonates was first introduced in the pediatric literature in an editorial in 1982⁸¹ and in reports of a specialized in-hospital program.^{82,83} Although hospice care at home or in an alternative setting for older children has been reported,⁸⁴⁻⁸⁷ such studies are lacking for neonates. However, the components of pediatric hospice care as expounded by Corr and Corr⁸⁸ are theoretically as equally applicable for infants, including 1) involvement of skilled professionals, 2) care directed toward control of distressing symptoms and provision of physical comfort, 3) coordination of services and a multidisciplinary approach, 4) adequate social supports to meet family needs, and 5) provision of follow-up and bereavement care. Enhancing the quality of the remaining life for the infant and family is more important than the site of care delivery.

DISCHARGE PLANNING

The care of each high-risk neonate after discharge must be carefully coordinated to provide ongoing multidisciplinary support of the family. The discharge planning team should include parents, the primary care physician, the neonatologist, neonatal nurses, and the social worker. Other professionals, such as surgical specialists and pediatric subspecialists, pediatric occupational, physical, speech, and respiratory therapists, infant educators, nutritionists, home health care liaisons, and a case manager selected by the team and family, may be included as needed.

The initiation of discharge planning should begin when it is evident that recovery is certain, although the exact date of discharge may not be predictable. The goal of the discharge plan is to assure successful transition to home care. Essential elements are a physiologically stable infant, a family who can provide the necessary care without undue strain and with appropriate support services in place within the community, and a primary care physician who is prepared to assume the responsibility with appropriate back up from specialist physicians and other professionals as needed.

Six critical components must be included in discharge planning.

1. Parental Education.

Parental contact and involvement in the care of the infant should have been encouraged from the time of admission. The participation of the parents in giving care as early as feasible in the neonatal course has been shown to have a positive effect on their confidence in handling the infant and readiness to assume full responsibility for the infant's care at home.⁸⁹

The development of an individualized teaching plan aids parents in acquiring the skills and judgment required for the appropriate care of their infant. Having a written checklist or outline of the specific areas and tasks to be mastered increases the likeli-

hood that both parents will receive complete instructions and experience. Caregivers and parents must understand that if an infant is discharged from the hospital before complete physiological maturation and resolution of all complications of high-risk birth, the infant's care requirements will continue at home. Furthermore, the level of care being asked of the parents is beyond that of the usual parental role. Thus, ample time for teaching the parents and caregivers the techniques and the rationale for each item in the care plan is essential. Return demonstrations, parent rooming-in, and telephone follow-up have all been reported to facilitate parental education and adaptation to their infant's care.^{15-17,21,89,90}

In so far as possible, at least two caregivers, one of whom is a responsible adult, should be identified and taught for each infant. The demands of home care can be physically and emotionally draining, especially at first, for infants requiring frequent feeding. Young mothers who do not live with a parent or the father of the baby have been shown to be vulnerable to the strains of home care.⁶⁷ Even in a two-parent family, the primary caregiver may become ill and need relief.

2. Implementation of Primary Care.

Preparing the infant for transition to primary care begins early in the hospitalization with administration of immunizations at the recommended ages,⁹¹ completion of metabolic screening,^{92,93} and assessment of hearing by an acceptable electronic measurement.⁹⁴ For the infants at risk, appropriate funduscopic examination for retinopathy of prematurity should be performed by an ophthalmologist skilled in the evaluation of the retina of the preterm infant as recommended in the AAP policy statement.⁹⁵ Assessment of hematologic status is recommended for all infants because of the high prevalence of anemia after neonatal intensive care. Because VLBW infants and those who have received parenteral nutrition for prolonged periods may be at risk for hypoproteinaemia, vitamin deficiencies, and bone mineralization abnormalities, screening for nutritional or metabolic deficiencies may be indicated.

3. Evaluation of Unresolved Medical Problems.

Review of the hospital course and the active problem list of each infant and careful physical assessment will reveal unresolved medical issues and areas of physiologic function that have not reached full maturation for the infant. From such a review, the diagnostic studies required to document the current clinical status of the infant can be identified and alterations in management instituted. The intent should be to assure implementation of appropriate home care and follow-up plans.

4. Development of the Home Care Plan.

Although the content of the home care plan may vary among the four categories of infants, the common elements include the following: 1) identification and preparation of the in-home caregivers, 2) development of a comprehensive listing of required equip-

ment and supplies and accessible sources, 3) identification and mobilization of necessary and qualified home care personnel and community support services, 4) assessment of the adequacy of the physical facilities within the home, 5) development of an emergency care and transport plan as indicated, and 6) assessment of available financial resources to assure the capability to finance home care costs. Specific details of planning home care for the technology-dependent infant are included in the AAP policy statement,⁹⁶ in a consensus report⁴⁸ and, for hospice care, in Corr and Corr.⁹⁷ The input of the primary care physician in formulating the home care plan of the technology-dependent infant is essential. Many infants, particularly the VLBW and technology-dependent infants, require continued care by multiple surgical specialists and pediatric subspecialists, each of whom should be included in the predischarge assessment and discharge planning.

5. Identification and Mobilization of Surveillance and Support Services.

The psychosocial characteristics of each family should be reviewed, noting those risk factors that may contribute to an adverse infant outcome. The availability of social support is essential to the success of every parent's adaptation to the home care of a high-risk infant.⁹⁸ Before discharge and periodically thereafter, a review of the family's needs, coping skills, use of available resources, financial problems, and progress toward goals in the home care of their infant should be evaluated. After the social support needs of the family have been identified, an appropriate, individualized intervention plan using available community programs, surveillance, or alternative care placement may be implemented.

6. Determination and Designation of Follow-up Care.

In general, the attending neonatologist has the responsibility for coordination of follow-up care, although in an individual institution, the tasks may be delegated to other professionals. A primary care physician should be identified as early as possible to facilitate the coordination of follow-up care planning between the primary care setting and the subspecialty center-based discharge planning staff. Pertinent information about the nursery course and home care plan should be given to that individual before the infant's discharge. It is highly desirable that the primary care physician meet the parents before the discharge and, if possible, examine the infant in the hospital. In specialty center units, the primary care attending physician should work together with the neonatologist in coordinating the discharge planning.

Arrangements for an initial appointment with the primary care physician should be initiated before discharge. Specific follow-up appointments with each involved surgical specialist and pediatric subspecialist should be made as indicated in advance of discharge, giving attention to grouping these as

much as possible to enhance compliance and to decrease the inconvenience of the family.

Periodic evaluation of the developmental progress of every infant is essential to identify deviations in neurodevelopmental progress at the earliest possible point, thereby facilitating entry into early intervention programs (Public Law 99-457).⁹⁹ The primary care physician with appropriate skills, the pediatric subspecialist, or clinic personnel may provide longitudinal developmental follow-up. When input from multiple disciplines is identified before discharge, a center-based clinic providing multidisciplinary care may be the least cumbersome option for the family.

SPECIAL CONSIDERATIONS

With networking among nurseries that provide different levels of care, increasing numbers of infants are transported back to community hospitals for convalescent care. In these hospitals, the discharge planning process should follow the same principles as those outlined above for an infant being discharged from a subspecialty center. Appropriate follow-up during the most critical periods for infants at risk for adverse sensorineural outcomes, ie, the VLBW infant for progression of retinopathy and for all high-risk infants whose hearing status or type of hearing deficit still needs evaluation.

Innovative programs based on community resources, both public and private, should be encouraged. The goal should be to provide coordinated care and family support. Efficient teamwork by health care professionals is imperative. Programs should be modified to accommodate different demographic needs and to achieve efficient use of all funding resources.

For optimal support of parents and surveillance of the status of a high-risk infant after discharge it is important that experienced nurses who are qualified to perform specialized assessments are utilized for home nursing visits. It is essential that previous performance and existing quality control programs be considered when choosing a home health care agency to provide personnel for in-home care of the technology-dependent infant.

RECOMMENDATIONS

The following recommendations are offered as a framework for consideration as each individual infant and caregiving situation is evaluated and the discharge decision made. It is prudent that each institution establish guidelines allowing for individual physician judgment and flexibility.

Infant Readiness for Hospital Discharge

In the judgment of the responsible physician there has been:

- A sustained pattern of weight gain of sufficient duration;
- Adequate maintenance of normal body temperature with the infant fully clothed in an open bed with normal ambient temperature (24°C to 25°C);

- Competent suckle feeding, breast or bottle, without cardiorespiratory compromise; and
- Physiologically mature and stable cardiorespiratory function of sufficient duration.

In addition,

- Appropriate immunizations have been administered;
- Appropriate metabolic screening has been performed;
- Hematologic status has been assessed and appropriate therapy instituted as indicated;
- Nutritional risks have been assessed and therapy and dietary modification instituted as indicated;
- Sensorineural assessments, hearing and funduscopy, have been completed as indicated;
- Review of hospital course has been completed, unresolved medical problems identified, and plans for treatment instituted as indicated.

Home Care Plan Readiness

An individualized home care plan has been developed with input from all the appropriate disciplines. The plan for infants with complex multiple system problems, and particularly for those requiring technological assistance, must be specific and detailed. For infants at psychosocial risk, arrangement for appropriate psychosocial surveillance and family support is essential.

Family and Home Environmental Readiness

Assessments of the family caregiving capabilities, resource requirements, and home physical facilities have been completed.

- Identification of at least two family caregivers, one of whom is an adult, and assessment of their ability, availability, and commitment;
- Psychosocial assessment for parenting risks;
- A home environmental assessment that may include an on-site evaluation;
- Review of available financial resources and identification of adequate financial support.

An on-site assessment documenting availability of 24-hour telephone access, electricity, and an in-house water supply and heating and detailed financial assessment and planning are essential in preparation for home care of the technology-dependent infant.

Parents and caregivers have demonstrated the necessary capabilities to provide all components of care including:

- Feeding, whether breast, bottle, or an alternative technique, including formula preparation as required;
- Basic infant care including bathing; skin, cord, and genital care; temperature measurement; dressing; and comforting;
- Infant cardiopulmonary resuscitation and emergency intervention as indicated;
- Assessment of clinical status, including understanding and detection of the general early signs and symptoms of illness, as well as the signs and

- symptoms specific to the infant's condition;
- Infant safety precautions including proper infant positioning during sleep and use of car seats¹⁰⁰⁻¹⁰²;
- Specific safety precautions for an artificial airway, feeding tube, ostomy, infusion pump, and other mechanical and prosthetic devices as indicated;
- Administration of medications, specifically proper dosage and timing, storage, and recognition of the signs and symptoms of toxicity;
- Equipment operation, maintenance, and problem-solving for each mechanical support device required;
- The appropriate technique for each special care procedure required, including special dressings for infusion entry site, ostomy, or healing wounds, maintenance of an artificial airway, chest physiotherapy, oropharyngeal and tracheal suctioning, and infant stimulation and physical therapy, as indicated.

Specific modification of home facilities as required by home care system needs have been completed.

Community and Health Care System Readiness

An emergency intervention and a transportation plan have been developed and emergency services providers identified and notified as indicated.

Follow-up care needs have been determined, appropriate providers identified, and appropriate communication exchanged including the following:

- Primary care physician identified, and responsibility for care of infant accepted;
- Surgical specialty and pediatric subspecialty follow-up care requirements identified and appropriate arrangements made;
- Neurodevelopmental follow-up requirements identified and appropriate referrals made;
- Home nursing visits for assessment and parent support arranged as indicated by the complexity of the infant's clinical status and family capability and the home care plan transmitted to home health agency.

The determination of readiness for care at home of an infant after neonatal intensive care is complex. Careful balancing of infant safety and well-being with family needs and capabilities is required while giving consideration to the availability and adequacy of community resources and support services. The final decision, which is the responsibility of the attending physician, must be tailored for the unique constellation of issues posed by each situation.

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