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CLINICAL REPORT

Postdischarge Follow-up of Infants With Congenital Diaphragmatic Hernia

Organizational Principles to Guide and Define the Child Health Care System and/or Improve the Health of All Children

Section on Surgery and the Committee on Fetus and Newborn

ABSTRACT

Infants with congenital diaphragmatic hernia often require intensive treatment after birth, have prolonged hospitalizations, and have other congenital anomalies. After discharge from the hospital, they may have long-term sequelae such as respiratory insufficiency, gastroesophageal reflux, poor growth, neurodevelopmental delay, behavior problems, hearing loss, hernia recurrence, and orthopedic deformities. Structured follow-up for these patients facilitates early recognition and treatment of these complications. In this report, follow-up of infants with congenital diaphragmatic hernia is outlined.

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Key Words
congenital diaphragmatic hernia, gastroesophageal reflux, pulmonary hypoplasia, follow-up

Abbreviations
CDH— congenital diaphragmatic hernia
ECMO— extracorporeal membrane oxygenation

INTRODUCTION

Survival rates for patients with congenital diaphragmatic hernia (CDH) have increased during the past decade with the implementation of more "gentle" ventilation and physiology-specific strategies, high-frequency ventilation, extracorporeal membrane oxygenation (ECMO), and improved supportive care.[1–3] Improvement in survival rates has occurred for infants with CDH complicated by severe pulmonary hypoplasia, pulmonary hypertension, and chronic lung disease.[4] However, other significant morbidities, such as neurocognitive delay, gastroesophageal reflux, hearing loss, chest wall deformity, poor growth, hernia recurrence, and complications attributable to associated congenital anomalies, continue to affect the lives of many infants with CDH beyond the neonatal period.[1,5,6]

Coordination of the complex medical and surgical needs of these infants is challenging. Comprehensive multispecialty clinics that aggregate specialty physicians and services are family-friendly and provide for collaborative evaluation and management planning. Same-site multidisciplinary service teams also improve coordination, communication, and support for the medical home pediatrician who is responsible for managing the general health care needs of the infant. Unfortunately, such multispecialty clinics are not available to all infants with CDH. The following information is intended to provide clinicians who care for infants with CDH with a template to organize a comprehensive plan for detection and management of associated morbidities.

PULMONARY MORBIDITY

Survivors with CDH may require treatment beyond the initial hospitalization for chronic lung disease, bronchospasm, pulmonary hypertension, aspiration, pneumonia, and pulmonary hypoplasia. Oxygen treatment beyond the initial hospitalization may be needed for many of these infants, especially those who are treated with ECMO and a prosthetic patch.[7–9] Many survivors not treated with ECMO also receive bronchodilators and inhaled steroids.[8] At least 4% of survivors require a long-term tracheostomy.[9,10] Nearly one fourth of infants with CDH who survive have obstructive airway disease at 5 years of age,[10,11] and some have pulmonary hypertension that persists for months or years. Pulmonary hypertension that persists for more than the first few weeks after birth is a risk factor for early death.[12] Persistent abnormalities in lung function also have been demonstrated on ventilation/perfusion scans.[8,12–15]

Pneumonia occurs in approximately 7% of infants with CDH during the first year after birth.[5,16,17] Aspiration-associated pneumonia and bronchospasm may be reduced in frequency by avoiding oral feeding if oromotor incoordination is significant and by early detection and treatment of gastroesophageal reflux. Pneumonia may be prevented in part by treatment for chronic lung disease, effective management of pulmonary secretions, and immunization with recommended childhood vaccines (such as pneumococcal, influenza, and other recommended vaccines). Palivizumab (respiratory syncytial virus monoclonal antibody; Synagis [MedImmune, Inc, Gaithersburg,

MD]) also is suggested for infants with CDH who have chronic lung disease, as described in the "Revised Indications for the Use of Palivizumab and Respiratory Syncytial Virus Immune Globulin Intravenous for the Prevention of Respiratory Syncytial Virus Infections" technical report and policy statement by the American Academy of Pediatrics.[18,19]

Although the incidence of chronic lung disease is 33% to 52% at discharge, most infants who survive CDH have clinical improvement over time.[6,16,17] Nevertheless, nearly 50% of adult survivors have impairment on pulmonary function testing.[16]

GASTROESOPHAGEAL REFLUX/FOREGUT DYSMOTILITY

Gastroesophageal reflux or some form of foregut dysmotility occurs in 45% to 90% of infants with CDH.[20–24] Abnormal hiatal anatomy at the gastroesophageal junction, lack of an angle of His in some patients, and herniation of the stomach into the chest with distortion are possible mechanisms to explain this high incidence of gastroesophageal reflux. Esophageal dilation or ectasia also has been described in some infants with CDH, and as many as 70% of such infants have severe gastroesophageal reflux.[21] The incidence of gastroesophageal reflux also correlates with defect size and need for patch repair.[20,25] Pulmonary morbidity may be worsened by aspiration associated with gastroesophageal reflux. Importantly, a high incidence of esophagitis in adult survivors with CDH suggests that long-term surveillance is needed.[26] For all patients with CDH, it is important to have a high index of suspicion for gastroesophageal reflux. Antireflux surgery may be an option for patients with failed medical therapy, although the long-term success rate of this procedure has yet to be proven.

GROWTH FAILURE

Many survivors with CDH fail to grow as well as healthy term infants do and require close nutritional surveillance and intervention.[6,9,20] Infants with CDH and chronic lung disease often have poor oral feeding skills. Gastroesophageal reflux is common, and oral aversion is frequent; both contribute to growth deficiency. In 1 clinical series, more than 50% of infants with CDH had weight below the 25th percentile.[20] Gastrostomy tube placement was performed in 33% of infants in this series. Van Meurs et al[6] showed that more than 40% of CDH survivors had weight below the 5th percentile at 2 years of age. Gastrostomy tube feeding is suggested by some experts who hypothesize that nasogastric or orogastric tube feeding impairs oral feeding. Others suggest use of nasogastric or orogastric tube feeding for a period of time, especially when success with oral feeding is anticipated within several months. Despite controversy about the most appropriate mode of feeding the infant with CDH at discharge, almost 33% do not orally feed enough fluid volume to support growth and receive feedings through nasogastric or gastrostomy tubes.[6,20] Early recognition and intervention is essential for optimizing both somatic and alveolar growth and long-term outcomes for infants with CDH.

NEUROCOGNITIVE DELAY AND BEHAVIORAL DISORDERS

Significant developmental delay and behavioral disorders have been reported for a large number of infants with CDH. The infant with a large diaphragmatic defect or need for ECMO is at greatest risk.[27–36] Nobuhara et al[27] reported developmental delay in more than 33% of their CDH survivors. McGahren et al[30] described neurologic abnormalities in 67% of infants with CDH who were treated with ECMO compared with 24% of infants with CDH who were not as ill and did not receive ECMO.

The critical illness and physiologic disruption of high-risk infants with CDH places them at risk of neurologic and developmental disabilities. Many infants who present with symptoms of CDH soon after birth are clinically unstable and hypoxemic and require high levels of extraordinary life support such as ECMO and other invasive therapies. Although severity of illness is most predictive of long-term outcome, complications associated with invasive therapies may contribute to morbidity in CDH survivors. In a study by Bernbaum et al[37] of survivors receiving ECMO, infants with CDH treated with ECMO had a higher risk of significant neurodevelopmental delays than did infants without CDH. The higher risk of disability in ECMO-treated survivors with CDH compared with ECMO-treated survivors without CDH suggests that at least 3 potential factors may contribute to neurodevelopmental disability in infants with CDH: (1) an intrinsic neurologic abnormality, (2) greater number and severity of morbidities that impair development in infants who require ECMO, (3) and a greater number of ECMO-associated complications.

HEARING LOSS

Sensorineural hearing loss has been described in a number of case series of CDH survivors[27,28,33,35] and seems to occur in infants regardless of whether they were treated with ECMO. The cause remains unknown, but it is speculated to be related to treatments for respiratory failure (such as hyperventilation, ototoxic medications, or neuromuscular blockade).[38] Severe hypoxemia, prolonged ventilation, and ECMO also are risk factors. Approximately half of infants with initially normal hearing assessments develop hearing loss later in infancy.[39–41]

HERNIA RECURRENCE

Recurrent diaphragmatic hernias have been reported in 8% to 50% of patients with CDH. The single-most important predictor of hernia recurrence is the presence of a large defect that requires a patch to repair.[2,6,42,43] Recurrences can present from months to years after the initial hospitalization, or the patient can remain asymptomatic. Detection of recurrences may be discovered incidentally on chest radiographs performed for surveillance or other reasons.[6,43] The lifetime risk of recurrence for a patient with a patch repair is unknown.

ORTHOPEDIC DEFORMITIES

Pectus deformities and progressive asymmetry of the chest wall have been described in CDH survivors.[27,28,44] The incidence of these orthopedic disorders ranges from

TABLE 1 **Recommended Schedule of Follow-up for Infants With CDH**

	Before Discharge	1–3 mo After Birth	4–6 mo After Birth	9–12 mo After Birth	15–18 mo After Birth	Annual Through 16 y
Weight, length, occipital-frontal circumference	X	X	X	X	X	X
Chest radiograph	X	If patched	If patched	If patched	If patched	If patched
Pulmonary function testing			If indicated		If indicated	If indicated
Childhood immunizations	As indicated throughout childhood	X	X	X	X	X
RSV prophylaxis	RSV season during first 2 years after birth (if evidence of chronic lung disease)	X	X	X	X	X
Echocardiogram and cardiology follow-up	X	If previously abnormal or if on supplemental oxygen	If previously abnormal or if on supplemental oxygen	If previously abnormal or if on supplemental oxygen	If previously abnormal or if on supplemental oxygen	If previously abnormal or if on supplemental oxygen
Head computed tomography or MRI	If (1) abnormal finding on head ultrasound; (2) seizures/abnormal neurologic findings[a]; or (3) ECMO or patch repair	As indicated	As indicated	As indicated	As indicated	As indicated
Hearing evaluation[44]	Auditory brainstem evoked response or otoacoustic emissions screen	X	X	X	X	Every 6 mo to age 3 y, then annually to age 5 y
Developmental screening evaluation	X	X	X	X		Annually to age 5 y
Neurodevelopmental evaluation	X			X		Annually to age 5 y
Assessment for oral feeding problems	X	X	If oral feeding problems	If oral feeding problems	If oral feeding problems	If oral feeding problems
Upper gastrointestinal study, pH probe, and/or gastric scintiscan	Consider for all patients	If symptoms	If symptoms	Consider for all patients	If symptoms	If symptoms
Esophagoscopy		If symptoms	If symptoms	If symptoms or if abnormal gastrointestinal evaluations	If symptoms	If symptoms
Scoliosis and chest wall deformity screening (physical examination, chest radiograph, and/or computed tomography of the chest)				X		X

The neurosensory tests performed and frequency of surveillance may differ among infants with CDH because of variability in neurologic, developmental, and physiologic impairments. Follow-up should be tailored to each infant. RSV indicates respiratory syncytial virus.
[a] Muscle weakness, hypotonia, hypertonia, or other abnormal neurologic sign or symptom.

21% to 48%. Many of them are mild and do not require surgical intervention. Scoliosis also has been found in these patients, with an incidence of 10% to 27%.[27,44] The incidence of both of these morbidities is higher in patients who have large defects and a patch repair. Periodic and regular follow-up is suggested to detect and prevent development of functionally significant deformities from developing.

OTHER CONGENITAL ABNORMALITIES

Additional congenital anomalies are present in approximately 40% of infants with CDH.[45–48] Congenital heart lesions account for nearly two thirds of these anomalies and have a major effect on risk of mortality.[45,48] Anomalies of the central nervous system, esophageal atresia, and omphalocele also are relatively prevalent compared with other organ systems. A number of syndromes and chromosomal anomalies (such as trisomies 21, 13, and 18; Fryns syndrome; Brachmann-de Lange syndrome; and Pallister-Killian syndrome) include CDH as one of the associated anomalies. Each of these anomalies and syndromes adds to the complexity and specialty care needs for affected infants. The care requirements for such infants necessitate individualized, multidisciplinary care plans.

SUMMARY

Survivors with CDH are at risk of a number of morbidities that may affect development and function. Infants with large defects, those who have received ECMO, or those with a patch repair are at highest risk. These unique patients, especially those at highest risk, require long-term periodic follow-up by a multidisciplinary team of medical, surgical, and developmental specialists to identify and treat morbidities before additional disability results. Preventive pediatric health care according to guidelines developed by the American Academy of Pediatrics is recommended for all children, including those with CDH.[49–52] To emphasize the importance of follow-up for specific morbidities associated with CDH, additional suggestions are provided (Table 1). These are most applicable to children with extraordinary medical and surgical complications associated with CDH and should be individualized depending on the specific needs of each infant.

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