# Follow Up Of Children With Congenital Diaphragmatic Hernia And Development Of A Multidisciplinary Care Program

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#### **Abstract**

#### Background:

There is wide variation in follow up practices after initial hospitalization and surgical repair of congenital diaphragmatic hernia (CDH) patients. We reviewed morbidities and follow up practices in our survivor cohort and implemented a new comprehensive CDH follow up program.

#### Methods:

This is a retrospective review of all CDH survivors from 2006 to 2010.

#### Results:

Twenty two patients were followed for 24 months to 5years of age. Three patients (11%) were on oxygen and 9 (34%) on gavage feedings at discharge. Variable frequency and length of follow up including screening test for growth and development was present. Nine (40%) develop pulmonary problems and 12 patients (54%) have feeding and growth issues. 8/17 (47%) patients assessed by standard neuro-developmental tests had mild to moderate motor and speech delay and receive therapy at 2 years of age.

Conclusion: Systematic long term multidisciplinary follow up may become the standard of care in CDH patients after initial hospitalization.

# INTRODUCTION

Congenital diaphragmatic hernia (CDH) is a rare and complex condition which carries high mortality and morbidity. It is increasingly recognized that patients with CDH and their families continue to struggle after surgical repair and initial hospitalization with a variety of problems for several years. These include cardiopulmonary issues, poor growth and nutrition, musculoskeletal problems, neurocognitive challenges and speech delay (1). Comprehensive and multidisciplinary follow up programs should be the focus of institutional resources aimed at improving CDH survival (2).

There is wide variation in CDH follow up practices across centers. It includes timing and frequency of follow up, use of various screening tools, including echocardiograms, chest radiographs, hearing screens and growth and developmental assessments. Additionally, physician providing the follow up care can be a primary pediatrician, neonatologist, developmental pediatrician or a pediatric surgeon (3).

More recently, large volume CDH centers (4) are focusing on developing comprehensive follow-up programs. Limited institutional resources are used efficiently to provide multispecialty care in a manner convenient to the families (1, 5). Consensus based recommendations are used to develop such programs (6). The aim of this study is to report morbidity in our survivor cohort, describe variation in follow-up and our efforts to develop a comprehensive multidisciplinary follow up program to implement the recommendations from the American Academy of Pediatrics.

#### **METHODS:**

Patients born with congenital diaphragmatic hernia, who survived initial hospitalization at St. Louis Children's Hospital from January 1, 2006- December 31, 2010, were included in this study. Retrospective data was collected from electronic medical charts after approval from institutional human research protection office (HRPO). Demographic data included perinatal characteristics,

hospitalization, surgical repair and morbidities at discharge. Post-discharge morbidities evaluated among this cohort included chronic lung disease, frequent wheezing episodes and pneumonia.

Chronic lung disease was defined as continued oxygen requirement after discharge. More than one wheezing episode treated with bronchodilators was defined as reactive airway disease. Use of inhaled steroids and courses of oral steroids were recorded. Episodes of pneumonia diagnosed and treated by the attending physician with antibiotics were recorded from the patient chart. Growth parameters, feeding difficulties and need for gastrostomy were also recorded. Patients who were treated with anti-reflux medications were presumed to have gastro-esophageal reflux. We also reviewed the frequency of repeat hospitalization, additional surgeries after discharge, duration of treatment for pulmonary hypertension, hearing screen and neurodevelopmental outcomes as evaluated by Denver Developmental scale of infant screen (DDSI-II) and Bayley Scale of Infant Development (BSID-III). Ongoing therapies after discharge were also recorded.

#### **RESULTS**

Cohort Demographics: Twenty six patients survived the initial hospitalization between January 1, 2006-December 31, 2010. Mean gestational age was  $37.6 \pm 2$  weeks with mean birth weight of  $3127 \pm 522$  g. Thirteen patients (50%) had a prenatal diagnosis and 16 (61%) were inborn. Left -sided CDH was present in 23 (88%) and 5 had liver herniation at surgical repair. Four had associated congenital anomalies of hypospadiasis, microcephaly, ventricular septal defect, pulmonary sequestration and Ebstein anomaly. Surgical repair was performed at mean age of  $11.8 (\pm 10)$ days after birth and a prosthetic patch was needed for repair in 9 (34%) patients. Four (15%) patients required extracorporeal membrane oxygenation (ECMO). The median length of hospital stay was 38.5 days (range 5-240 days) and median ventilator days was 20.5 days (range 4-185 days).

Brain imaging studies consisted of head ultrasound (25), brain MRI (6) and head CT (2) which was performed in 25 (96%) patients. Abnormal head ultrasound showed intraventricular and intraparenchymal bleed, echogenic foci and prominent ventricular size, while brain MRI showed intraventricular and parenchymal hemorrhage previously missed on head ultrasound, punctate signal of periventricular leucomalacia, diffuse white matter changes and generalized brain atrophy. Head CT scans showed parieto-occipital

stroke in both studies. The overall significance of the abnormal neuro-imaging finding and its correlation with long term developmental outcome is still unclear and needs more prospective studies.

Three patients (11%) were discharged on supplemental oxygen while 9 (34%) needed supplemental gavage feedings. Eleven (42%) patients were on sildenafil after discharge for a median of 4 (3-8) months. Eighteen (69%) patients were discharged on anti-reflux medications (Table 1)

**Table 1**Patient Demographics

| Clinical Data  | N= 26,                                |
|--|---------------------------------------|
|  | N (%) or mean ± SD                    |
| Gestational Age ( week)  | 37.6 ± 1.98                           |
| Birth weight (g)   | 3127 ± 522                            |
| Prenatal Diagnosis   | 13 (50)                               |
| Inborn (%)   | 16 (61)                               |
| Hernia Side, left  | 23 (88)                               |
| Liver Herniation   | 5                                     |
| Major associated congenital anomalies  | 4 (15)                                |
| Karyotype available  | 9 (30)                                |
| Time to surgery (d)  | 11.84 ± 10.6                          |
| Patch repair   | 9 (34)                                |
| Need for ECMO  | 4 (15)                                |
| Median Ventilator support (d), median( range)  | 20.5 (4-185)                          |
| Median Length of stay (d)  | 38.5 (5-240)                          |
| Neuro-imaging ( HUS, MRI, CT)  | 25                                    |
| Abnormalities on head ultrasound     Abnormalities on brain MRI     Abnormalities on head CT | 4/25 (16%)<br>3/6 (50%)<br>2/2 (100%) |
| Supplemental O2 at discharge   | 3 (11)                                |
| Feeding tube at discharge  | 9 (34)                                |
| Sildenafil at discharge  | 11 (42)                               |
| Anti-GER medication at discharge   | 18 (69)                               |
| Physical and occupational therapy arranged at discharge                                      | 10 (38)                               |
| Multispecialty appointments at discharge   | 20 (76)                               |

# Follow-up Outcomes

Twenty two patients were followed after discharge. The length of follow up varied between 24 months and 5 years. Four patients did not return for follow-up and were unable to be contacted. During this time period, patients were mainly seen in the surgery clinic. Neonatal high risk clinic visits were few, typically on different days with variability in screening methods and duration of follow up (Table 2).

Table 2a

#### Outcomes

| Outcomes   | N (%)   |  |
|--|---------|--|
| Growth (n = 22 )   |         |  |
| Weight below 50 <sup>th</sup> %tile                              | 13 (59) |  |
| Weight below 25th %tile  | 9 (40)  |  |
| Weight below 10 <sup>th</sup> %tile                              | 6 (27)  |  |
| Weight below 3™ % tile   | 3 (13)  |  |
| Pulmonary  | 9 (40)  |  |
| Reactive airway disease  | 9 (40)  |  |
| Pneumonia  | 4 (18)  |  |
| Chronic Lung Disease   | 0       |  |
| Recurrent CDH requiring Surgery                                  | 2 (9)   |  |
| Recurrent surgery in patch repaired patients                     | 1       |  |
| Additional Surgery required                                      | 11 (50) |  |
| Pulmonary hypertension requiring sildenafil at discharge         | 10 (45) |  |
| Duration of Sildenafil treatment after discharge, months, median | 4 (3-8) |  |
| Echocardiographic Follow up in patients on sildenafil            | 9 (90)  |  |
| Last echocardiogram after discharge, months, median              | 4 (3-8) |  |

#### Table 2b

| Gastrointestinal                                | 12 (54)               |
|---|-----------------------|
| Gastrostomy feeding                             | 4 (18)                |
| GER   | 7 (31)                |
| Fundoplication                                  | 3 (13)                |
| Constipation                                    | 5 (22)                |
| Oral Aversion                                   | 4 (18)                |
| Laparotomy for bowel obstruction                | 2 (9)                 |
| Musculoskeletal                                 | 11 (50)               |
| Pectus excavatum                                | 8 (36)                |
| Torticollis                                     | 1                     |
| Chest wall deformity                            | 3 (13)                |
| Scoliosis                                       | 1                     |
| Talipes equinovarus                             | 2 (11)                |
| Neurodevelopmental Evaluation completed (n= 17) | 8/17 NDI <sup>1</sup> |
| Hearing Problems                                | 4                     |
| Vision Problems                                 | 2                     |
| Gross motor delays                              | 4                     |
| Fine motor delays                               | 5                     |
| Cognitive delays                                | 3                     |
| Speech and language delays                      | 6                     |
| Therapy requirements at 24 months               | 7 (41)                |

NDI: Neuro- developmental impairment

Growth and Gastrointestinal Problems: Nine (40%) patients weighed below the 25th percentile at 24 month follow-up, while 3 patients weighed below the 3rd percentile. Twelve patients continued to have gastrointestinal issues at follow-up. Four (18%) patients continued to need gavage feeds with oral aversion and 7 patients continued to have symptoms of

gastro esophageal reflux (GER) at 24 months receiving anti-reflux medications.

Pulmonary and Cardiac Problems: Three patients discharged home on supplemental oxygen were successfully weaned off by 24 months. Nine (40%) patients continued to have pulmonary issues mainly consisting of reactive airway disease requiring bronchodilator treatments. Four patients were treated for pneumonia with oral antibiotics. Additional Surgeries and Hospital Admissions: Two (9%) patients including 1 with patch repair developed recurrent CDH requiring surgical repair. Eleven (50%) patients required additional operative procedures including abdominal wall hernia repair (2), lysis of adhesions for small bowel obstruction (2), hypospadias repair (2), orchidopexy (2), gastrostomy insertion (3), tonsillectomy (1) and strabismus correction (1).

Musculoskeletal Deformities: Eleven (50%) patients had variety of musculoskeletal deformities including pectus excavatum (8), flaring of lower ribs presenting as chest wall asymmetry (3), scoliosis (1) and talipes equinovarus (2). Neurodevelopmental Problems: In the cohort of 22 patients, DDST-II was performed at 12 and 24 months of age in 18 and 11 patients respectively (Table 3).

Table 3

Denver Developmental Scale of Infant at 12 and 24 months follow up

|                                     | DDSI at 12 months | DDSI at 24 months |
|-------------------------------------|-------------------|-------------------|
| Patients assessed by DDSI in clinic | 18                | 11                |
| Motor delays                        | 6 (33%)           | 5 (45%)           |
| Language delays                     | 6 (33%)           | 8 (72%)           |
| Social delays                       | 0                 | 0                 |

Five (45%) patients out of 11 who were screened had motor delay at 24 months while language delay was noted in 8 (72%) patients.

Bayley Scale of Infant Development (BSID-III) was administered at a median age of 19 (12-25) months to 17/22 (72%) of the survivor cohort and showed (Tables 2 and 4) that eight (47%) had impairment in at least one of the motor, language or cognitive scores. Based on individual scores, average, mildly delayed and severely delayed scores in cognitive skills were found in 76%, 11% and 5% while language delay was found in 64%, 23% and 5% of the surviving cohort. Psychomotor scores were normal, mildly delayed and severely delayed in 58%, 17% and 7% of the cohort.

Hearing screen was performed in 11/22 (50%) patients at 12 months and showed mild hearing loss in 6 (54%) of those tested. Only nine patients had hearing screen at 24 months and showed that two (22%) patients had mild hearing loss. All of the patients had passed their hearing screen prior to initial hospital discharge.

**Table 4**Standardized testing using Bayley Scale of Infant Development- Version III

| Patients who completed standardized Bayley<br>assessment | N= 17                  |
|--|------------------------|
| Mean age in months at Bayley ± SD, median<br>(range)     | 18.8 ± 4.5, 19 (12-26) |
| Motor Scores: mean, SD, median                           | 92 ± 12, 94 (61-110)   |
| Cognitive Scores: mean, SD, median                       | 93 ± 10, 95 (70-110)   |
| Language Scores: mean, SD, median                        | 93 ± 10, 91 (71-112)   |

**Table 5a**Schedule for comprehensive follow up at CDH Clinic

| Discharge Planning Meeting                              | before initial hospital discharge with family  Every 6 months in the first 2 years, then annually /more frequent if  clinically indicated: |  |
|---|--|--|
| CDH Clinic Visits                                       |  |  |
| Patients on supplemental oxygen and/ or gavage<br>feeds | Monthly visits   |  |
| Patients on supplemental gastrostomy feeds              | <ul> <li>Visits every 3-d months. Telephone consultation every<br/>month for weight gain and feeding adjustment</li> </ul>                 |  |
| <ul> <li>Patients with oral aversion</li> </ul>         | Every 4-6 months. Feeding evaluation may be done   |  |
| Patients on sildenafil                                  | Every 3 months with echocardiogram if previously<br>abnormal. Echocardiogram prior to cessation of sildenafil.                             |  |
| Growth and Nutrition                                    | At each visit assessment of:  Weight, Length and Head Circumference  Caloric goals and need for supplementation                            |  |
| Chest Radiograph ( per AAP)                             | Every 3-6 months for patched repair for recurrence until 2 years<br>Annual after 2 years   |  |
| RSV Prophylaxis ( per AAP)                              | Patients with CLD/RAWD in the first 2 years  |  |
| Hearing Evaluation ( per AAP)                           | Every 6 months till age 3, then annually to age 4-5  |  |

#### Table 5b

| Neuro | developmental Evaluation  |  |
|-------|---|--|
|       | Pre-discharge neurological examination Pre-discharge Brain MRI (per AAP)                      | With family and therapist to develop home plan     Patients with abnormal exam, head ultrasound, seitures and ECMO |
| •     | Neurological examination  | At each clinic visit   |
|       | Denver Developmental Screening test ( DDST-II )   | At each clinic visit   |
|       | Bayley Scale of Infant Development (BSID-III)   | <ul> <li>Atlyearsage</li> </ul>  |
| •     | Wechsler Intelligence Scale for Children(WISC-IV) and<br>Vanderbilt Screening for ADHD        | Defore starting school (4-5 year age)  |
|       | al screening for scollosis and chest wall deformity by<br>nation and if indicated Radiographs | Starting at 9 months and then annually   |

## **DISCUSSION**

Improved survival from CDH- Study group and high volume centers have been reported recently (7, 8). Several factors including antenatal diagnosis, delivery and postnatal care at a high volume center, delayed surgical repair, lung protective ventilation strategies, availability and use of various new pulmonary vasodilators and collaborative effort among physicians and surgeons have shown to have a positive impact on patient survival (9-11).

High morbidity among survivors of CDH with complex medical and surgical problems has been documented extensively. These problems typically include pulmonary morbidity from prolonged mechanical ventilation and exposure to inflammatory mediators in the setting of pulmonary hypoplasia. Significant numbers of patients develop chronic lung disease (CLD), reactive airway disease and are at a high risk of hospitalization with respiratory viral illnesses. In addition, there is a persistent need for bronchodilators and inhaled steroids. The reasons for pulmonary morbidity are multifactorial and include severity of pulmonary hypoplasia with reduced number of bronchi and alveoli along with abnormal pulmonary vasculature in both the ipsilateral and contralateral lung. Ventilator induced lung injury (VILI) and exposure to high concentrations of oxygen although decreased, with the adoption of "gentle ventilation" and "permissive hypercapnia" by several centers continues to be an important factor in the development of CLD (12). Chest radiographs after repair commonly show lung hyperinflation. Similarly, pulmonary function tests have revealed obstructive and restrictive patterns of lung disease in CDH survivors when compared with healthy controls (13).

Pulmonary hypertension (PH) is recognized as an important contributor of overall mortality among CDH patients. Resolution of PH occur in 50% of the patients who do not need extracorporeal membrane oxygenation (ECMO) by

three weeks of age (14). There is very little data on the influence of PH on overall morbidity among CDH survivors. In one study by Iocono (15), resolution of PH was observed in 6 out of 40 patients by 12 months. It is unclear whether PH was symptomatic in their cohort and how frequently the echocardiograms were performed after discharge. There is lack of data regarding suggested duration of pulmonary vasodilator treatment and frequency of echocardiographic follow up after discharge. A recent study (16) suggested no significant differences in childhood morbidity in CDH patients with and without PH in the neonatal period.

A common but less understood morbidity is GER with its associated nutritional and growth sequelae. GER is reported between 30-81% of long term CDH survivors. It has shown to cause significant growth failure despite attempts to increase caloric intake. It is an important contributor toward the development of oral aversion (17). In a retrospective study by the French CDH Study group (18), prophylactic fundoplication at the time of CDH repair among patients needing patch significantly reduced the incidence of growth failure at 1year follow up( 3% vs. 38%). There is lack of management consensus in these patients. Routine assessment with height, weight, growth velocity and early dietary and feeding team interventions are suggested by several studies (1, 17).

Musculoskeletal deformities like pectus excavatum, chest wall asymmetry and mild scoliosis occur in patients with anatomically large size diaphragmatic defects. It is suggested that tension at the time of repair may interfere with normal development of the thoracic cage and promotes asymmetric chest wall development (19). Similarly creation of more negative intra thoracic pressure due to increase work of breathing in these patients also promotes retraction in the most compliant portion of the chest wall (19).

Progressive sensorineural hearing loss (SNHL) is reported in 15-90% of the CDH survivors (7). The wide range in incidence is due to different definitions, age at testing and method of hearing screen used. The overall prevalence of hearing impairment exceeds that of the general population (0.1-0.2%)(20), and in high risk NICU patients (1-3%) (21). A study by Morini et al in 2008 (22), showed that at their non –ECMO center, 49% of CDH survivors had SNHL when tested at a mean age of 4 years. They identified associated sepsis, hypoxia, hypocapnia, high frequency oscillatory mode of ventilation (HFOV), inhaled nitric oxide (iNO), and use of aminoglycoside and muscle relaxant to be the risk factors. Unfortunately, data regarding associated

speech and language problems if any and further intervention in the SNHL group was not provided. Frequent hearing evaluation, starting at 6 month until 3 years of age is recommended by American Academy of Pediatrics (6) for early detection and intervention in patients with SNHL.

Reports of high incidence of neurodevelopmental impairment (NDI) with or without ECMO in both early (6–36 months) and later (9-15 year) age emphasize the importance of long term follow up (3, 5, 23, 24). Neurodevelopmental evaluation was available in 17 out of 22 patients. These patients were typically followed by neonatal high risk clinic in addition to surgery clinic. The frequency of the follow up and screening tests performed during the visits was variable and at the discretion of the attending neonatologist.

The high incidence of morbidities and variability in postdischarge care among our survivor cohort led to the development of a comprehensive multidisciplinary CDH follow up program at our institution.

The program was developed in collaboration with pediatric surgeons, cardiologists, dietitian, therapist and a neonatologist who was designated to be responsible for the follow-up. A systematic follow up care plan (table 5) was proposed drawing from the original guidelines set forth by American Academy of Pediatrics in 2007. The practical logistics of enabling multidisciplinary care givers at each visit (such as scheduling conflicts) were resolved and the care plan was implemented in February 2012. Pre Discharge planning meetings with the family and the CDH clinic team (neonatologist, nurse coordinator and dietician) were scheduled to review long term follow up plan and individual patient goals. At each clinic visit, the primary surgeon for the child and a single neonatologist perform the examination. Visits to the clinic are scheduled every 6 months at a minimum and more frequently if indicated. Parents are encouraged to call or email 24/7 with various questions and concerns to the neonatologist and the clinic nurse coordinator, resulting in timely resolution of parental concerns and avoidance of unnecessary emergency room or clinic visits. Screening chest radiographs, hearing evaluation as per AAP guidelines and developmental screen using DDST-II are performed at each visit. Feeding problems and growth velocity is closely monitored. Predischarge brain MRI is obtained and standardized developmental testing using BSID-III is performed at 24 months of age on all the CDH survivors by a pediatric psychologist. Echocardiogram is performed in patients

discharged on oral sildenafil prior to its discontinuation. Multidisciplinary follow up will continue until the child reaches 5 years of age.

Systematic evaluation at a high volume center with experts from various specialties and consistent long term follow up will hopefully lead to early recognition of disabilities. In summary, this study describes and confirms the morbidities present in the CDH patients long after their initial hospital discharge. It also describes development of a structured, multidisciplinary follow up program in a high volume CDH center to identify best practices to improve long term outcomes and optimize the use of diagnostic modalities during follow up.

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