Neurodevelopmental and Oral Feeding Outcomes for Infants born with Single Ventricle Physiology requiring Surgery

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Single Ventricle Heart Defects

A child with a single ventricle defect is born with a heart with only one ventricle that is large enough or strong enough to pump effectively. Single ventricle heart defects include:

- Tricuspid Atresia
- Double outlet Left Ventricle
- Some heterotaxy defects
- Hypoplastic Left Heart Syndrome
Diagnosis

In most cases, children with single ventricle heart defects require intensive medical intervention soon after birth. Symptoms vary depending on the severity and type of defect. They include:

- Blue or purple tint to lips, skin and nails (cyanosis)
- Difficulty breathing
- Difficulty feeding
- Lethargy (sleepy or unresponsive)
- Often diagnosis is made before the baby is born
Single Ventricle Repair Options

• Single ventricle defects require a series of open heart procedures, over several years, called “staged reconstruction.” Surgeons reconfigure the heart and circulatory system.
After Surgery

• After the operations for single ventricle defects, the heart functions like a one-sided pump with two chambers. The heart no longer receives deoxygenated blood from the veins. Instead, this blood flows directly to the lungs. The heart receives oxygenated blood from the lungs and pumps it to the body.
Incidence

• In the United States, over 35,000 infants are born each year with CHD, and more than a third of these infants are expected to undergo temporary or corrective surgical interventions in the first year of life.
Impact of CHD on Brain Development

- Clinical and radiographic evidence of impaired preoperative neurologic status
- In utero cerebral flow characteristics and compensatory mechanisms
- Congenital brain and developmental abnormalities
- Genetic abnormalities
- Structural brain abnormalities
- Acquired preoperative brain injury

Neurodevelopmental Outcomes

• As a group, children with complex CHD (CHD severe enough to require surgery or other interventions in the first few months of life) have a higher likelihood of experiencing problems related to neurodevelopmental issues compared to children without CHD
Neurodevelopmental Outcomes

- Children with single functioning ventricle who undergo a series of palliative surgical procedures culminating in the Fontan are at the highest risk of neurodevelopmental compromise

Neurodevelopment issues

May include problems affecting

• Behavior
• Social interaction
• Motor skills
  – Large motor (clumsiness, coordination)
  – Fine motor (drawing, cutting, handwriting)
• Academic performance
• Speech and language development
• Feeding
Neurobiology of oral feeding and swallowing

• Peak synaptogenesis of the medulla is seen at 34-36 weeks gestation
• By 35-38 weeks, nervous system matures sufficiently enough to carry out some integrative functions to include nipple feeding
Oral Feeding Challenges

• Oral feeding challenges are heightened during the post operative surgical period while the infant is recovering.
• These infants experience growth failure which negatively impacts the infant’s cognitive and socioemotional growth.
• Parental anxiety and confidence (Einarson & Arthur, 2003; Lawoko & Soares, 2002).
Research Focus

Studies on neurodevelopmental outcomes of infants with CHD have focused on:

• Factors related to surgery (Circulatory arrest time, cross clamp time, deep hypothermic circulatory arrest, time of ventilation, hospitalization, techniques of surgery)

• Increasing body of literature examining prenatal factors


• No studies to date examining caregiving practices after surgery
What is hypoplastic left heart syndrome (HLHS)?

- HLHS is a congenital heart condition that is fairly rare. HLHS occurs in approximately 1 in 5000 babies and accounts for 1% of all congenital heart disorders.

- The left ventricle (the pumping chamber) is small and the Mitral and/or the Aortic valve may be narrow, blocked or not formed at all.

- The Aorta is often small (Hypoplastic).

- And there is a hole (Atrial Septal Defect) between the two collecting chambers.

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HLHS

• The deoxygenated blood flows into the Right Atrium, through the Tricuspid Valve into the Right Ventricle
• From there it is pumped up to the lungs where the blood receives oxygen
• The oxygen-filled blood then flows from the lungs into the Left Atrium, but it will be unable to then pass into the Left Ventricle as the valve is blocked or narrowed
• The blood therefore passes through the hole between the two ventricles into the right side, where it mixes with the deoxygenated blood and follows the normal path to the lungs
• While the Ductus Arteriosus is still patent, the blood will pass from the pulmonary artery into the aorta and then around the body
• When the duct closes, the baby will no longer have oxygen flowing to their body. Gradually they become sicker and die

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Possible treatments for HLHS

• Surgical treatment – Staged reconstruction: Norwood, Glenn, Fontan
• Supported comfort care
• Transplantation

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HLHS

Atrial septal defect

Small aorta

Blocked aortic valve

Blocked mitral valve

Hypoplastic left ventricle

Hypoplastic aorta
Norwood Procedure

• Usually preformed within a few days of birth
• Aims of the Norwood:

(a) To improve the flow of oxygenated blood around the body by attaching the base (Trunk) of the Pulmonary Artery to the Aorta. It may be necessary to enlarge the Aorta with a patch.

(b) To provide a blood flow to the lungs through a passage (Shunt), creating a link between the Pulmonary Artery and the Aorta. The passage is made out of Gore-Tex

(c) To create a permanent passage (septectomy) between the collecting chambers (Left and Right Atrium) ensuring that a mix of oxygenated blood and deoxygenated blood is flowing around the body

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Norwood

(b) Shunt is formed

(a) Trunk of the pulmonary artery is attached to the aorta

(c) Enlarge the atrial septal defect
Cavo Pulmonary Shunt (Glenn Shunt)

• As the children grow, they will require a more permanent supply of blood to their lungs than earlier surgical procedures can provide.

• A Cavo Pulmonary Connection is normally performed between three and nine months of age.

• The aim of this operation is to redirect the flow of deoxygenated blood to the lungs by attaching the Superior Vena Cava directly on to the Pulmonary Artery.

• The Gore-Tex shunt that was inserted at the last operation will be taken away.

www.lhm.org.uk
The final stage of surgery will be performed as the child starts to show that they need more blood flow to the lungs. They may become more breathless on exercise or their growth may slow down. This is done around three years of age.

The Fontan Procedure aims to separate the deoxygenated blood supply and the oxygenated blood supply.

Although this does not make the heart function normal, it does allow the children to grow and enjoy more physical activity.
Caregiving Model

• The brains of infants with congenital heart disease appear more similar to those of premature newborns than to the brain of typical term infants


• Caregiving model similar to one used in NICU that has been shown to improve brain development and neurodevelopmental outcomes – evidence based approach
Goals of Caregiving

- Parents-child relationship must be fostered
Paradigm

- Our best chance at optimizing children’s developmental trajectories, and the associated probabilities of school readiness, is by intervening early and consistently throughout early childhood with evidence-based interventions demonstrated to support social-emotional development through nurturing, responsive interactions with caregivers.
Paradigm

• Substantial evidence indicates that consistent, high quality interactions with caregivers beginning in infancy and continuing throughout early childhood makes a profound difference in children’s developmental outcomes as well as in long-term savings in human cost and social expenditures (Isaacs, 2008; Kagan & Newman, 2000; Landry et al, 2001; Lyons-Ruth, Melnick, 2004; Smith, Landry & Swank, 2006)
Environment
Complex Congenital Heart Disease Clinic

- Neonates and infants born with complex congenital heart disease requiring surgical palliation within first days of life, those with single ventricle palliation, or those undergoing hybrid procedures toward single ventricle palliation
- Team includes MD, PhD, PNP, CSW, RD
- Patients seen weekly post discharge
- Home monitoring program
- BSID administered every 3 months
Complex Congenital Heart Disease Clinic

• Screening for at-risk children with single ventricle physiology
• Neurological and developmental evaluation, diagnosis and intervention
• Help for families finding programs and resources in their communities
• Education for pediatricians, pediatric cardiologists and other community healthcare providers to increase understanding of the needs of children with CHD
• Data collected and shared for establishment of international guidelines for neurodevelopmental evaluation and care of children with complex congenital heart defects
• Effective tracking mechanisms to help us learn and refine care for future patients
Bayley Scales of Infant Development

- Individually administered examination
- Assesses the current developmental functioning of infants and toddlers when they reach 18 months of age
- The primary value is in diagnosing developmental delay and planning intervention strategies
- Used to assess current developmental status rather than to predict subsequent ability levels
<table>
<thead>
<tr>
<th>Subtest</th>
<th>Composite Score</th>
<th>Percentile</th>
<th>Classification</th>
<th>Age Equivalent</th>
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</thead>
<tbody>
<tr>
<td>Cognitive</td>
<td>105</td>
<td>63</td>
<td>average</td>
<td>16 mos</td>
</tr>
<tr>
<td>Motor</td>
<td>100</td>
<td>50</td>
<td>average</td>
<td></td>
</tr>
<tr>
<td>Fine Motor</td>
<td></td>
<td></td>
<td></td>
<td>18 mos</td>
</tr>
<tr>
<td>Gross Motor</td>
<td></td>
<td></td>
<td></td>
<td>12 mos</td>
</tr>
<tr>
<td>Language</td>
<td>121</td>
<td>92</td>
<td>superior</td>
<td></td>
</tr>
<tr>
<td>Receptive</td>
<td></td>
<td></td>
<td></td>
<td>20 mos</td>
</tr>
<tr>
<td>Expressive</td>
<td></td>
<td></td>
<td></td>
<td>17 mos</td>
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</tbody>
</table>
Neurodevelopmental Outcomes of Infants with Single Ventricle Physiology

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Children’s Hospital Colorado and University of Colorado, Anschutz Medical Campus, CO

Background
Children born with single ventricle physiology typically have poor neurodevelopmental outcomes.

Purpose
To evaluate:
- Changes in infants’ Bayley scores from 6 to 12 months
- Relationship between medical variables to 12 month Bayley Scores
- Relationship of Bayley scores to oral feeding variables

Methods
- Retrospective chart review of 52 infants with single ventricle physiology requiring surgical repair
- All patients placed in one of two diagnostic groups:
  1) Single LV – (N=22) tricuspid atresia, Ebsteins, PA/IVS, DILV
  2) Single RV – (N=30)HLHS, DORV
- Medical variables included: gestational age, age at surgery, weight at surgery, cross clamp, DHCA and cerebral perfusion time, length of stay and days on ventilator
- Feeding variables included: consultation to OT, SLP and ENT, swallow studies, UGI, and feeding method
- Bayley domains included Cognitive, Speech and Motor

Results

Changes in Bayley scores from 6 – 12 months
- N= 16 infants tested at both 6 & 12 months
- Single LV = 37.5% (N=6)   Single RV = 62.5% (N= 10)
- Paired t-tests

<table>
<thead>
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<th>Variable</th>
<th>6 Month Mean (SD)</th>
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<td>93.38 (11.53)</td>
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<td>Motor</td>
<td>94.06 (21.67)</td>
<td>96.44 (18.32)</td>
<td>t = 0.70, p = 0.492</td>
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Medical Variables to Bayley scores
Bivariate correlations of surgical variables to the Bayley scores
+p<.10.*p<.05, **p<.01, ***p<.001

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<tr>
<th>Variable</th>
<th>Cognitive</th>
<th>Language</th>
<th>Motor</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total LOS</td>
<td>r = 0.02</td>
<td>r = -0.33+</td>
<td>r = -0.64***</td>
</tr>
<tr>
<td>Days on Ventilator</td>
<td>r = -0.12</td>
<td>r = -0.37*</td>
<td>r = -0.51**</td>
</tr>
</tbody>
</table>

Feeding Variables to Bayley scores
- No feeding variables were related to Cognitive scores at 6 or 12 months.
- Full oral feeding (breast and/or bottle) at discharge was related to higher motor scores
  (t = 2.37, p = .025) as compared to infants who were tube fed.

  - Single LV
  63.6% oral feeding at discharge and 36.4% required feeding tube to go home.
  - Single RV
  23.3% oral feeding at discharge and 76.7% required feeding tube to go home.

Discussion

- The mean scores for neurodevelopmental outcome domains tested were in the normal range with trending decline in Cognitive and Motor scores at 12 months
- A variety of medical and surgical variables were examined as correlates of the 12 month Bayley scores. No medical/surgical variables were correlated with Bayley scores except Cognitive and Motor score declined with longer LOS and more days on ventilator
- Infants with Single LV required a tube (nasogastric or gastrostomy) to be able to be discharged home as compared to infants with Single LV
Presentation/Publication

*6th World Congress: Pediatric Cardiology & Cardiac Surgery. Cape Town, South Africa, February 17 – 22, 2013: Neurobehavioral Outcomes of Infants seen in Complex Congenital Heart Disease Clinic.

Background

• Surgical techniques for infants with congenital heart disease (CHD) have improved allowing for palliative or corrective procedures in the neonatal period (Einarson & Arthur, 2003).

• Infants born with CHD have immature and smaller brains (Massaro et al, 2008).

• Children born with single ventricle physiology typically have poor neurodevelopmental outcomes.
Background - Additional Syndromes

- DiGeorge
- Alagelle
- Shone Complex
- VACTERL
- Trisomy 21
- Turner
- Klinefelter
- Ebstein
Purpose

To evaluate:
• Changes in infants’ Bayley scores from 6 to 12 months
• Relationship between medical variables to 12 month Bayley Scores
• Relationship of Bayley scores to oral feeding variables
Methods

• Retrospective chart review of 52 infants with single ventricle physiology requiring surgical repair August 2009 – July 2011
• All patients placed in one of two diagnostic groups:
  1) Single LV – (N=22) tricuspid atresia, Ebsteins, PA/IVS, DILV
  2) Single RV – (N=30) HLHS, DORV
• Medical variables included: gestational age, age at surgery, weight at surgery, cross clamp, DHCA and cerebral perfusion time, length of stay and days on ventilator
• Feeding variables included: consultation to OT, SLP and ENT, swallow studies, UGI, and feeding method
• Bayley domains included Cognitive, Speech and Motor
Post operative Complications

• DIC
• Shock
• Chylothorax
• Sepsis
• Pacemaker
• Arrhythmia with treatment
• NEC, including C-diff, bloody stools, pneumomotosis
• Seizures, PVL or other brain anomalies
• Surgical complications including abscess, peritonitis
• DVT
• renal
<table>
<thead>
<tr>
<th></th>
<th>Mean (SD) or # (%)</th>
<th>Range</th>
<th>Median</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gestational Age</strong></td>
<td>38.10 (2.03)</td>
<td>33-41</td>
<td>39</td>
</tr>
<tr>
<td><strong>Age at Surgery (in Days)</strong></td>
<td>10.03 (14.42)</td>
<td>2-91</td>
<td>5</td>
</tr>
<tr>
<td><strong>Complications</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>10/51 (19.%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>One</td>
<td>25/51 (49.02%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&gt;1</td>
<td>16/51 (31.4%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Total LOS</strong></td>
<td>37.38 (25.87)</td>
<td>0-106</td>
<td>30</td>
</tr>
<tr>
<td><strong>CICU LOS</strong></td>
<td>27.62 (22.65)</td>
<td>2-99</td>
<td>18</td>
</tr>
<tr>
<td><strong>Clamp Time (% yes in parantheses)</strong></td>
<td>38.82 (34.03) (66.7%)</td>
<td>0-124</td>
<td>46</td>
</tr>
<tr>
<td><strong>DHCA Time (% yes in parantheses)</strong></td>
<td>13.55 (21.79) (60.8%)</td>
<td>0-111</td>
<td>4</td>
</tr>
<tr>
<td><strong>Cerebral Perf Time (% yes in parantheses)</strong></td>
<td>16.04 (23.91) (37.3%)</td>
<td>0-75</td>
<td>0</td>
</tr>
<tr>
<td><strong>Weight at Surgery</strong></td>
<td>3.12 (.68)</td>
<td>2.01-6.33</td>
<td>3.06</td>
</tr>
<tr>
<td><strong>Days on Ventilator</strong></td>
<td>19.71 (22.12)</td>
<td>0-136</td>
<td>12</td>
</tr>
<tr>
<td><strong>UMBS (% yes)</strong></td>
<td>11/51 (21.6%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>ENT Consult (% yes)</strong></td>
<td>11/52 (21.2%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Bottle prior to surgery (% yes)</strong></td>
<td>30/52 (57.7%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Breast Feeding at Surgery (% yes)</strong></td>
<td>13/52 (25%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Audiology, Left Ear (% refer)</strong></td>
<td>4/46 (8.7%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Audiology, Right Ear (% refer)</strong></td>
<td>7/46 (15.2%)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Changes in Bayley Scores from 6 to 12 Months

- Bayley scores at the 6 month follow up = 20
- Bayley scores at 12-month follow-up = 29
- Bayley scores at both time points = 16
- For those with data at both time points, paired t-tests were used to compare mean Bayley scores from 6 months to 12 months.
- Marginally significant decrease in Cognitive and Language scores over time and no change in Motor scores.
## Changes in Bayley scores from 6 – 12 months

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- N= 16 infants tested at both 6 & 12 months
- Single LV = 37.5% (N=6) Single RV = 62.5% (N = 10)
- Paired t-tests
Relationship of Surgical Variables to 12 month Bayley Scores

• A variety of surgical variables were examined as correlates of the 12 Month Bayley scores.
• None of the surgical variables were correlated with the Cognitive Subscale.
• There was evidence that greater total LOS, greater CICU LOS, and a greater number of days on a ventilator were all related to lower Language and lower Motor scores at 12 months.
• None of the other surgical variables were related to Language or Motor scores.
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</tr>
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<tr>
<td>Gestational Age</td>
<td>-0.08</td>
<td>-0.05</td>
<td>0.15</td>
</tr>
<tr>
<td>Age at Surgery (in Days)</td>
<td>-0.003</td>
<td>-0.05</td>
<td>-0.13</td>
</tr>
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<td>0.02</td>
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<td>0.13</td>
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<td>-0.01</td>
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<td>DHCA Time</td>
<td>0.07</td>
<td>-0.09</td>
<td>0.16</td>
</tr>
<tr>
<td>Cerebral Perf Time</td>
<td>0.23</td>
<td>-0.12</td>
<td>-0.14</td>
</tr>
</tbody>
</table>

+p<.10, *p<.05, **p<.01, ***p<.001

The bivariate correlations of the surgical variables to the Bayley scores
Relationship of Surgical Variables to 12-month Bayley Scores

In addition, the following categorically measured surgical variables were examined in terms of their relationship to the Bayley scores using independent samples t-tests:

- Surgery Category (Category 1 versus Categories 2 and 3 Combined)
- Complications (yes or no)
- Diagnosis Category (1 or 2)
- Pulse Ox at Discharge (yes or no)

None of these t-values were significant, indicating that none of the categorically measured surgical variables related to any of the three Bayley outcomes measured at 12 months.
Relationship of Feeding Variables to 12- month Bayley Scores

The following feeding variables were examined based on their relationship to the 3 Bayley subscales at 12 Months:

- UMBS (yes or no)
- ENT Consult (yes or no)
- Feeding Method at Discharge (Breast and/or Bottle versus Other)
- Enyeral feeding (yes or no)
- Bottle prior to surgery (yes or no)
- Oral feeding amount (Oral feeding amount divided by total LOS)
Relationship of Feeding Variables to 12-month Bayley Scores

• No feeding variables were related to Cognitive scores.

• Having an ENT consult was related to lower Language \( (t = 2.61, p = .015) \) and Motor \( (t = 2.29, p = .03) \) scores.

• Breast and/or bottle feeding compared to another feeding method was related to higher Motor scores \( (t = 2.37, p = .025) \).

• No other feeding variables were related to Bayley scores.
Relationship of Surgical Variables to Feeding Variables

Surgical Variables:
- Surgery Category (Category 1 versus Categories 2 and 3 Combined)
- Complications (yes or no)
- Diagnosis Category (1 or 2)
- Clamp Time (yes or no)
- DHCA Time (yes or no)
- Cerebral Perfusion Time (yes or no)

Feeding Variables
- UMBS (yes or no)
- ENT Consult (yes or no)
- Feeding Method at Discharge (Breast and/or Bottle versus Other)
- Enteral feeding (yes or no)
- Bottle prior to surgery (yes or no)
Relationship of Surgical Variables to Feeding Variables

• The next slide shows a table indicating the percent responding yes to the feeding variables across the surgical variable categories.

• Those in surgery category 2 or 3, those with no complications, and those with diagnosis category 1 were significantly more likely to be bottle or breast fed at discharge compared to those in surgery category 1, those with complications or those with diagnosis category 2.

• Those with a clamp or cerebral perfusion during surgery were more likely to have an ENT consult.
Cross tabs were calculated to examine the relationships between the surgical variables with feeding variables. The table shows the percent responding yes to the feeding variables across the surgical variable categories. The * indicates a significant chi-square value (*p<.05, **p<.01).
Discussion

- The mean scores for neurodevelopmental outcome domains tested were in the normal range with **trending decline** in Cognitive and Motor scores at 12 months.
Discussion

• A variety of medical and surgical variables were examined as correlates of the 12 month Bayley scores. No medical/surgical variables were correlated with Bayley scores except Cognitive and Motor score declined with longer LOS and more days on ventilator.
Discharge Planning

• Single LV
  – 63.6% oral feeding at discharge and 36.4% required feeding tube to go home.

• Single RV
  – 23.3% oral feeding at discharge and 76.7% required feeding tube to go home.
Implications for Practice

• Timing of repair
• Research on caregiving practices including:
  ✓ Consistent parental presence- holding, enfolding, olfactory inputs
  ✓ NIDCAP philosophy – examination of physiological, motor and state systems
  ✓ Kangaroo care & Pumping
• Focus on feeding experience NOT volume