Interstage Monitoring

“Home Surveillance Monitoring”

WHO, WHY & HOW

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48th Annual Southeast Pediatric Cardiology Society
Birmingham, Alabama
September 26, 2015

Disclosure Statement

I do not have any relevant financial relationships with any commercial interests to disclose

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Single Ventricle Hearts

-Birth ….. Adulthood
Most Fragile

Lifelong care is MANDATORY

Hypoplastic Left Heart Syndrome
Survival to Discharge

- Until 1980s: HLHS 100% fatal
- Palliations: Norwood
- Improved survival
- Advances: Surgical, medical management

Babcock-Tausig
Shunt

Sano (PV to PA) Shunt

Hybrid: PDA Stent & PA bandings
NO newborn – CP Bypass

Neonatal Single Ventricle Cardiac Surgery
Jan., 2011 – Dec, 2014

- Death: Prior to discharge home

- 15.27 % Norwood
- 24.7- 34.3% Hybrid Stage I (HLHS)
- 22.8% Damus-Kaye-Stansel (DKS)
- 7 % – 10.8% Shunts (MBTS - Central shunt)
- 10 % Pulmonary artery band

SITES: > 90 % survival to discharge!
"Interstage Period"

- INTERSTAGE: Period of time
- After discharge to HOME from Norwood, shunt
- Presentation for second stage operation
  - AGE BDG ~ 4 - 5 months
  - Some > 6-9 mo., + Bi-V repair

**10 - 24% Risk for Death**

- INTERSTAGE
  - After discharge home
  - Norwood: 10 - 24%
  - Hybrid: ____%

**INTERSTAGE**

- After discharge home
- Hybrids: __%
- Before second stage operation (4-5 mos old)
- HIGHER RISK than post-op mortality

ADD REFERENCES!


WHY

Interstage Monitoring

Risk: Circulatory Collapse & Death

- Single Ventricle Physiology... even at home
- LIMITED circulatory reserve

**CAN Lead to:** Progressive low oxygen delivery & ventricular dysfunction

E. R. & CICU

- "SIMPLE"
  - Gastroenteritis, vomit
  - Dehydrated
  - Resp. infection
  - Thrush... < PO

- CARDIAC
  - Valve leaks
  - Arrhythmias
  - Re-Coarc
  - Worse RV Function

Single Ventricle: Interstage Death

Potential Causes

- Hypovolemia & progressive HYPOXEMIA
- Common childhood illnesses
- Dehydration Even if Mild - AGGRESSIVE MANAGEMENT
  - Vomiting, diarrhea
  - Fever
  - Upper resp infection / RSV
  - Caution: DIURETIC therapy... > dry

Result: Shunt thrombosis, death

ADD ARTICLES 2014 & 2015 HERE
Case Studies

WHAT can happen after discharge home?

Interstage Period

Case Study: Anthony - Norwood, 3 m

E.R.: Poor P.O., crying, blue

• 175 HR
• BP "OK": 97/43
• RR: 76 & dyspnea
  • Gray
• Sats: 69-71% sats
  • (Rebreather)
• CICU admit
• IVF
• Primacor & Bicarb

Lactate

CRITICAL Fact - ONLY Source
PULMONARY Blood Flow

• Goretex Tube:
  • Norwood
  • Sano (RV to PA’s)
  • Stansel
• PDA stent:
  • Hybrid Stage I

Interstage: Clotted Goretex Shunt

Clot in shunt

• Progressive, sudden - profound cyanosis
  Baby G, 2 mos., ... required mechanical support

Always NARROWING Risk
SHUNT PDA STENT

SURVEILLANCE ... @Home ---- ER, CICU!

Limiting pulmonary blood flow ... LOWER arterial saturations

5 mos, BDG
12 Mos - TOF complex

Case Study
2 mo., Carlos Guerrero

• s/p Norwood
  • Home 1 month... Doing well! wt. gains ~ 30 gm/day
• MOM phone REPORTS: Jan, 2014
  • < intake
    • 24 oz/day
    • 19 oz/day
    • 15 oz/day... new fussiness, < rest... RE - ADMIT direct
**Severe decrease function, Re-coarctation
in Norwood..... Primacor, Urgent CATH < next AM..... BDG & Aortic Revision < 36 hrs.**
Recoarctation: Early or Late

- HLHS Residual or
  - Recurrent obstruction
  - Aortic Arch
- 2% * - 37% NEW #
- POORLY tolerated*
- Can lead to decreased ventricular function
- Excessive PBF (sats>90%)
- < Systemic flow

Fuller, Card in Young, 2011:21(Supp2); Kutty, et al., Cath Card Int, 2011: 78(1); Lamers, JTCVS, 2012:143(5)

“Seconds … MINUTES MATTER”

“Red Flag Signs” Palliated HLHS Infants

- May PRECEDE
  - BOTH!! In-patient & Out-patient!
- Sudden
  - HEMODYNAMIC COLLAPSE
- Difficult resuscitation
  - …. MUST AVOID THIS!

HOW ?

Interstage Monitoring

Detect EARLY subtle changes in HLHS infant at home?

Started at Children’s in Wisconsin, 2000

Research

GOALS: Interstage HLHS Care

DAILY Home Monitoring

- EARLY, timely detection symptoms & treatment
- PRIOR to deterioration … ER, emergent care
- Focus… Family education - preparation

- JACC, 59(1) Supp. S; 2012;
- Rudd, 2015, JTCVS

“RED FLAG” Symptoms of DANGER

Hypoplastic Left Heart

- CALL TEAM 24 hr./day IF:
  - < PO intake
  - Saturation: < 75% or > 90%
  - Weight LOSS: 30 grams + in 3 days
  - Failure to gain 20 grams in 3 days
  - Vomit, diarrhoea

Borrie, Card in Young, 21(S2), 2011; Helen Card Young,21(S2), 2011

NOW USED FOR: ALL Single Ventricle Palliations

Same s/s

Clinic….. CICU…ER
**Interstage Monitoring**

- **BEGAN:** HLHS Palliation
  - Children’s of Wisconsin – Nov., 2003

- **NOW**
- **NATIONAL BEST PRACTICE**

Kugler, et al., Cong Heart Disease, 4(3): 2009; http://jcchdqi.org

- **1st work:** Hypoplastic Left Heart Syndrome
- **National MULTI-CENTER QI Project**
  - 2010 Begun Team recruitment
  - **WORK TOGETHER,** team training
  - Introduce improvements in fragile HLHS
  - Protocols, developed- experts, evidence based
  - **DECREASE** our variability of performance

Collaborate, Analyze & Incorporate Best Practices

**GOAL:** Improve outcomes HLHS interstage
- Improve interstage growth, nutrition
- Reduce readmissions & death
  - due to major medical adverse events
- Improving Care Transition: Out Patient
  - Parent preparation
  - Effective communication between caregivers (Out Patient)

WHO?

**Interstage Monitoring**

- **HLHS**
  - **Provided:** Many Centers
  - ALL Single Ventricle palliated newborns
**HOW?**

Interstage Monitoring

Detect EARLY subtle changes in HLHS infant at home?
*Started at Children’s in Wisconsin, 2000*

**Research**

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**Team Work!**

- Multidisciplinary
- Rounds q Tuesday

**NPC - QIC**

- “Break down tasks”
- STEP By …
- STEP

**Interstage Care TEAM**

- January, 2006
- In-Patient: Teaching, Family prep
- Close home surveillance NP
- Single OUT PATIENT
  - Monday
  - Saturday

**Family Education**

INTERSTAGE

Home Surveillance Monitoring

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**Add other JH photo:**

My Heart Journey Home

BEGIN AT ADMISSION! ...... continues
EVERY SINGLE SHIFT!
ENCOURAGE: Parent chose a block …
HELP them Start .... & .... Do
...... Formula, meds, “red flags”, NG…“JOURNEY BOARD”
Each Hospital ...

**NURSING Discharge “Checklist”**

- **Must AVOID** last 24 hour
  - (C) RUSH!
  - Meds +
  - CPR +
  - Recipes formula … oil, cereal, +
  - NG, GT care
  - Correct use sat monitor, feed pumps, scales ……

The **BINDER** for Home Care!

- 2004
- Paper folders!!!
- “Cheap”
- “Red Flag” Lists
- Feed logs
- Support group
- Synagis
- Development …A PEN!

USE **“TEACH BACK”**

**PRACTICE… PRACTICE…**

**… MORE PRACTICE!**

USE **“TEACH BACK”**

- **Repetition** of Behaviors, Concepts
- **Reinforcement**

**USE TEACH BACK TECHNIQUES**

- “I want to be sure I was clear.”
  - Can you **tell me**, in your own words, how you should give the baby this medication?”
  - Show me how to …. **Prepare** the aspirin pill, lasix
  - Show me how….Mix the formula …

Verify their understanding & performance of tasks

**… Do the **REAL THING** ! = 90% retention**

**DO NOT ASK:**

**DO YOU UNDERSTAND ?
“Do you have any questions?”**

**NATIONAL PEDIATRIC CARDIOLOGY**

Quality Improvement Collaborative | a JCCHD initiative
**RED FLAGS SIGNS**

*“RED FLAG” Symptoms List*

- MD Name/Office #
- "RED FLAG" Danger Symptoms List
- Trained observe specific signs to call
- Report interstage team
- Trigger evaluations by multidisciplinary team
- 24 hr/day...7 days/week

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**Parent Home Surveillance: Observations**

*Single Ventricle Newborn*

- "RED FLAG" Danger Symptoms List
- Trained observe specific signs to call
- Report interstage team
- Trigger evaluations by multidisciplinary team
- 24 hr/day...7 days/week

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**“RED FLAG” Symptoms of DANGER Hypoplastic Left Heart**

NOW USED FOR: ALL Single Ventricle Palliation

- CALL TEAM 24 hr./day IF:
  - < PO intake
  - < 75% or > 90% Saturation
  - Weight LOSS: 30 grams + in 24 hours
  - Failure to gain 20 grams in 3 days
  - Vomit, diarrhea

Ghanayem, et al., 126, 2003, TCVS; JACC, 59(1) Supp. S; 2012; Boris, Card in Young, 21(S2), 2011; Hehir, Card Young, 21(S2), 2011

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**Single Ventricle Staged Palliation**

- Newborn: Shunted
- Expected arterial 02 sats: 75-90%
- At risk for death & morbidity
- After discharge home ... Even If "Look Good"
- Home monitor: "Red Flag" Danger signs
  - Poor feeding
  - Oxygen saturation < 75% or > 90%
  - Respiratory difficulty
  - Diarrhea, vomiting

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**Early ID s/s ... Avoid EXTREMIS**

- Guidelines

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**“Oxygen Level in the Blood”**
Train Parents: Interstage SV Care
DAILY Home Monitoring

- Use NCH monitor
- UNTIL home machine arrives
- EXPECT: 75-90%
- May be higher
- Practice all FOUR extremities

Saturations
Heart rate … for minutes

WATCHING TRENDS!

- CALL IF:
  - Saturations DIFFERENT than usual
    - 10% change
    - < 75%
    - OR > 90%
  - RESTING- Heart rates changing?
    - HIGHER than normal? …. STRESS?

Daily Logs…. TRENDS

Oxygen Use at Home?

- Norwood – Sano
- 0.5 L/min

COMPLEX….. Practice -- CRUCIAL! ...
...ILLITERATE

Nutrition Plan: Interstage Care

Registered Dietician - KEY
-BOTH: In Pt. & Out Pt.

FEEDINGS

“Last clinical hurdle … before discharge home”
**Going Home Book**

**RECIPES: Formula & Breast Milk**

**Breast Milk and Formula Preparation**

<table>
<thead>
<tr>
<th>mL/ml</th>
<th>24 cal/oz</th>
<th>50 cc q 3 hours</th>
</tr>
</thead>
<tbody>
<tr>
<td>20</td>
<td></td>
<td></td>
</tr>
<tr>
<td>24</td>
<td></td>
<td></td>
</tr>
<tr>
<td>28</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Mixing Formula**

- 24 cal/oz
- Enfamil Infant
- Breastmilk

**Practice… Mixing Formula**

- Mix the formula concentration your doctor prescribed in the infographic.
- Add water specified by the clinic.’s computer.
- Titrate to the specified ounces with syringe/automatic feed.

**Record EACH FEED**

- **ADD**
- **Daily Total:**

**Discharge HOME:**

**GIVEN A “TARGET” for Feedings!**

- **# ML per feeding**
- **# Ounces/24 hour day to feed**

**Home Care**

- **Single Ventricle**
- **HLHS Newborns**

**MCH - Feeding Goals**

- **HLHS Newborns**
- **Goal:** 20-30 grams/day weight gain

**Angel: Norwood - Sano**

- **BW:** 2.60 kg
- **2 mos D/C:** 2.92 kg
- **< 0 %**
- **Home:** GT ….PO
- **BDG:** 8.24 kg (7 mos)
- **33.7%**
- **GAINS 31 gm/day!**
Home WEIGHTS ..... DAILY

- Same time
- Naked
- BEFORE feed
- EXPECT DAILY
- AT LEAST!
- ½ - 1 oz increase
- 30 grams

Weekly- INCREASE
FEED GOALS & Daily VOLUMES
As weight increases…. NG, GT!

Single ventricles: Nutrition

WHY such focus?

Hemodynamic Compromise
... Poor ventricular function,
arch obstruction

HLHS – MANIFEST simply
as FEEDING INTOLERANCE

ER PLAN … Binder

- Identify
- Best local ER to Use
  - ER #
  
  - Out Pt. Cardiologist
  - CELL PHONE #
  
  - CARDIAC ICU#: 24 / 7

Single Ventricle Communication

- Wallet ID
- Parent Education
- All contact # s
- Express condition
- “Red Flags” - Sats
- Car seat tag

ALERT: EMR Cerner

- Each SV infant
- At discharge home
- * SAFETY Alert
- Floats, ER, OR
ER PLAN
Single Ventricle Patients

• REINFORCE TO FAMILY
• NORMAL arterial oxygen saturation

DO NOT GIVE...
SUPPLEMENTAL OXYGEN to raise sats > 90%!!!

• 75% - 90%
• ALL Single Ventricle palliations

MEDICATIONS

Medications

LIST MEDS . . . in Cell Phone File

• What --- WHY
• Preparation
• ONE type of syringe!
• TIMING
  • What to give together!
• Vomiting plan
  • NO "repeating med"
• ACTION PLAN: CALL MD
  • < PO, vomiting, diarrhea...... DANGER diuretics, vasodilators

MED ERRORS @ home

• AVOID them!
• CHANGE TIMES
  • Daytime meds only!
• PRACTICE DRAWING UP each med
• USE WATER!

• Hadi .... Zantac dose
  • 10 X prescribed...... MUST PRACTICE!!
    .....multiple times

Interstage Home Med Review

• TEXT message
• Verify

INFECTION CONTROL

ALWAYS!
It's OK to LOOK!
But please, DO NOT TOUCH the way. Thank You.
Immunizations & Infections

- **Synagis**
  - RSV season
  - 5 / year
- **ILL CONTACTS …. Avoid them!**
- **Routine immunizations**
  - Wait ~ 4 weeks post discharge
  - Council: CLOSE monitor – s/s reaction
    - Tylenol q 4 hours & monitor fevers, irritability
    - Oral feeds – maintain

DEVELOPMENTAL SUPPORT

Quote Mussatto

Article Marino/ AHA

Neuro – Cardiac Developmental Plan: Single Ventricle

ACHIEVE FULLEST POTENTIAL

PT, OT SP

- Florida - “Early Steps”
  - Ordered: By 4 months of age
  - Or soon
- **MCH**
- Neurocardiac Developmental Clinic
  - March, 2013
  - Ann Byslop, MD - Neurologist
  - .... “EVEN IF they look OK”

CALL

Dr. Patagne, Cardiologist
Phone: 561-558-1212

Jo Ann
Phone: 786-414-0751

24 hours Cardiac ICU
Phone: 1-800-666-4278

Interstage Home Monitoring Logs

Good Signs

<table>
<thead>
<tr>
<th>DATE</th>
<th>Oxygen level</th>
<th>Heart beats per minute</th>
<th>WEIGHT</th>
<th>Feeding</th>
<th>TOTAL ounces per 24 hours</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tuesday</td>
<td></td>
<td>120-150</td>
<td>7 - 8 +</td>
<td>+ +</td>
<td>6 g 9 ++</td>
</tr>
</tbody>
</table>
Interstage Home Monitoring Logs

- Bad Signs & Must Call Doctor

<table>
<thead>
<tr>
<th>DATE</th>
<th>Oxygen level in Blood %</th>
<th>Heart beats per minute</th>
<th>WEIGHT</th>
<th>Feeding: TOTAL ounces per 24 hour day</th>
</tr>
</thead>
<tbody>
<tr>
<td>Monday</td>
<td>&lt;75%</td>
<td>120 b.p.m.</td>
<td>6 lb 9 oz.</td>
<td>6 oz. bottles each day</td>
</tr>
<tr>
<td>Tuesday</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Wednesday</td>
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<td>Thursday</td>
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<td>Friday</td>
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<td></td>
</tr>
<tr>
<td>Monday</td>
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<td></td>
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</tr>
</tbody>
</table>

Illiterate Home Monitoring Log

Home Information Progress?  
Journey Board

MUST “ROOM – IN”

- Demonstrate independent care

TEAM Work

MUST ROOM - IN

ANTICIPATORY … Collaboration

- Standardized
- Demand Highest Level
- Multidisciplinary
- Transition from
- In-Patient to
- OUT-PATIENT CARE

- Prepare PED MD
- SV care ....Never seen
- Norwood, Hybrid
- Plan PRIMARY care
- Feeds, immunizations
- Pre-Discharge conference CALLS
- Articles, guide, diagrams
- FAX D/C info
- Ped MD & Cardiologist
Interstage Monitoring Home CALLS - CONTACTS
• ~ Q week or ... DAILY
• Electronic transmission - Text
• Assess progress... feeds, weight, saturations
• Problem detection... solving
• Formula mix... WICC?
• Reinforce “Red Flags”
• F/U done?
• Loss of medicaid, insurance
• No transportation?
Some Key Accomplishments

- **Improved Outcomes:** Interstage Growth & Nutrition

  *Nutrition Bundle: Weighted scale, home visits, phone contacts, post-hospital follow-up*

  *90% of infants now have satisfactory interstage weight gain*

INCREASED re-admissions associated with:
Genetic syndrome, Hybrid, small/medium volume centers

37% Infection Requiring IT Antibiotics

Retrospective Review RE-ADMISSIONS

- Cardiac Arrest
- Shunt Occlusion
- Life Threatening Arrhythmia
- Seizures
- Stroke
- Aspiration

37% Infection Requiring IT Antibiotics

**Digoxin Use & Improved Survival**

Use of digoxin associated with decreased Interstage Death
In patients with no history of arrhythmia

**RESOURCES ONLINE**

Patients & Care Teams

MANY more ....!
CONCLUSION
INTERSTAGE MONITORING HLHS
Evolved ....
Single center..... Multicenter QI
Best Practice: Red Flags

CRUCIAL Role Nursing
Discharge Teaching for Interstage Home Monitoring Care
.... Continue the positive results in survival, growth, care transitions
Family & Out Pt. Care Team

Risk: Circulatory Collapse & Death
- Single Ventricle Physiology... even at home
- LIMITED circulatory reserve
- Inefficient parallel circulation
- Development of “issues”... > RISK

“SIMPLE”
- Gastroenteritis, vomit
- Dehydrated
- Resp. infection
- Thrush... < PO

CARDIAC
- Valve leaks
- Arrhythmias
- Re- Coarct
- Worse RV Function

Train Parents: Interstage SV Care
DAILY Home Monitoring
Saturations
Heart rate.... for minutes
Nutrition, Feeding intake
Weights

“RED FLAGS” List of Symptoms
- ALERT Family
- WHAT condition
  - Expected 02 Sats
- WHEN CALL
- WHO call 24/7
- Copy baby room

MUST Practice & KNOW THIS ALL
BEFORE DISCHARGE!
... Repetition is KEY

Interstage Monitoring
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