Coping with Congenital Heart Disease: Implementation of an Evidence-Based Intervention in a Pediatric Cardiac Intensive Care Unit

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Coping with Congenital Heart Disease: Implementation of an Evidence-Based Intervention for Caregivers in a Pediatric Cardiac Intensive Care Unit

Tori Raphael, BSN, RN
Final DNP Project Presentation
INTRODUCTION AND BACKGROUND
Introduction
Significance of the Problem

**Caregiver**
- >60% of parents develop acute stress disorder
- >80% experience signs and symptoms of PTSD
- Feelings of overwhelming fear and worry

**Patient**
- Reduced resilience
- Slower recovery time & longer lengths of stay
Purpose & Goals

• Implement an evidence-based coping intervention for parents of children admitted to the pediatric cardiac intensive care unit

• Inspire the development of a standardized practice at the project site
Guiding Model and Theory: The Model of EBP Change & Lippitt’s Change Theory
PICOT Question

In parents of patients admitted to the pediatric cardiac intensive care unit (P), how does the application of an educational, behavioral, or combined program (I) compared to usual care (C) affect parental coping skills (O) during hospitalization (T)?
Search Strategy

Step 2: Locate the Best Evidence

- Records identified through database searching: PubMed (n=74), CINAHL (n=108), PsyInfo (n=59)
- Additional records identified through other sources (n=0)

- Records after duplicates removed (n=225)
- Records screened (n=40)
  - Full-text articles assessed for eligibility (n=14)
    - Studies included for critical appraisal (n=7)
      - Studies included in synthesis of literature (n=14)

- Records excluded (n=26)
  - Full-text articles excluded, with reasons (n=7)
    - Intervention did not begin or take place until after discharge. (n=3)
    - Intervention was designed to improve coping among the patients rather than their caregivers. (n=3)
    - Intervention did not take place in a critical care (ICU) setting. (n=1)

- Systematic review articles (n=6)
  - Articles assessed for eligibility from systematic review articles (n=51)
    - Study intervention did not take place until after discharge, study was not a randomized controlled or quasi-experimental design, intervention was not performed towards population of interest, was a duplicate, or did not evaluate an outcome of interest (n=38)
      - Studies included for critical appraisal (n=13)
Step 3: Critically Analyze the Evidence

Evidence Synthesis

Evidence Level & Quality

- Levels I-II
- Quality A/B
Interventions

- Congenital Heart Disease Intervention Program (CHIP)
- 5 step individualized face to face program
- Mother-infant attachment program
- Early palliative care
- Mother-nurse partnership program
- Information sheet
- Family centered care
- Creating opportunities for parent empowerment program (COPE)
- Online interactive training course and relaxation techniques
- Kangaroo Care & Skin-to-Skin
- Wearing Scent Cloth

Outcomes

- Anxiety
- Worry
- Coping
- Stress
- Depression
- Mother-Infant Attachment
- Maternal-Health related quality of life
- Perceived family functioning
- Parental satisfaction
- Self efficacy
- Perceived mother nurse partnership
- Parental confidence
- Support for child
- Negative Mood State
- PTSD symptoms
- Social support

Step 3: Critically Analyze the Evidence

Evidence Synthesis
Step 3: Critically Analyze the Evidence

Qualitative Research, Clinical Expertise, Patient Preferences, & Values

• Qualitative study themes: decrease parental stress by using coping strategies & a holistic approach

• Patient and family-centered care

• Consider the complexity of cardiac diagnoses
Recommendations for Practice

Implement an educational/informational intervention targeted towards improving psychological symptoms and coping for caregivers during their child’s admission.

Implement a multi-phase or multi-step intervention targeted towards improving psychological symptoms and coping for caregivers during their child’s admission.

Implement an intervention that has been specifically tailored for caregivers of children diagnosed with congenital heart disease.
Step 4: Design Practice Change

Early Palliative Care for Maternal Stress in Infants Prenatally Diagnosed with Single-Ventricle Heart Disease
Step 4: Design Practice Change

Setting
Step 4: Design Practice Change

Patients/Participants
Ethical Considerations
Step 5: Implement and Evaluate Change in Practice

IMPLEMENTATION
Step 5.1: Assess Change Agent’s Motivation and Resources

Early Palliative Care for Maternal Stress in Infants Prenatally Diagnosed with Single-Ventricle Heart Disease
Intervention

• 1st consultation- within 2 weeks of admission and prior to surgery
  • Introduce palliative care team, complete palliative care team assessment, answer caregiver questions and concerns

• 2nd consultation- within 48 hours of surgery
  • Individualize care by providing patient and family support, education, and anticipatory guidance both during and after hospitalization

• 3rd consultation- within 1 week of surgery
  • Individualize care by providing patient and family support, education, and anticipatory guidance both during and after hospitalization
Intervention

- Kit Items:
  - Guided questions tool to ask medical team
  - Comfort items for parents and patients
  - How to connect with local heart families

Step 5.2: Select Progressive Change Objective
OUTCOMES & EVALUATION
<table>
<thead>
<tr>
<th>Sights and Sounds</th>
<th>Baby Looks and Behaves</th>
<th>Parental Role</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. The presence of monitors and equipment</td>
<td>1. The unusual color of my baby</td>
<td>1. Being separated from my baby</td>
</tr>
<tr>
<td>2. The constant noises of monitors and equipment</td>
<td>2. My baby’s unusual or abnormal breathing patterns</td>
<td>2. Not feeding my baby by myself</td>
</tr>
<tr>
<td>3. The sudden noises of monitor alarms</td>
<td>3. My baby being fed by an intravenous line or tube</td>
<td>3. Not being able to care for my baby myself</td>
</tr>
<tr>
<td>4. The other sick babies in the room</td>
<td>4. The limp and weak appearance of my baby</td>
<td>4. Feeling helpless about how to help by baby during this time</td>
</tr>
<tr>
<td></td>
<td>5. Jerky or restless movements of my baby</td>
<td>5. Not having time to be alone with my bay</td>
</tr>
<tr>
<td></td>
<td>6. My baby not being able to cry like others</td>
<td></td>
</tr>
<tr>
<td></td>
<td>7. Having a machine breathe for my baby</td>
<td></td>
</tr>
</tbody>
</table>

(Barr, 2017)
### Caregiver Demographics

<table>
<thead>
<tr>
<th>Demographic Variable</th>
<th>Frequency (out of 8 Total Caregivers)</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Ethnicity</strong></td>
<td>White (3)</td>
<td>White (37.5%)</td>
</tr>
<tr>
<td></td>
<td>Black or African American (2)</td>
<td>Black or African American (25%)</td>
</tr>
<tr>
<td></td>
<td>Native American (2)</td>
<td>Native American (25%)</td>
</tr>
<tr>
<td></td>
<td>Asian (1)</td>
<td>Asian (12.5%)</td>
</tr>
<tr>
<td><strong>Insurance</strong></td>
<td>Medicaid (7)</td>
<td>Medicaid (87.5%)</td>
</tr>
<tr>
<td></td>
<td>Group/Employer Sponsored (1)</td>
<td>Group/Employer Sponsored (12.5%)</td>
</tr>
<tr>
<td><strong>Household Income</strong></td>
<td>Less than $20k (2)</td>
<td>Less than $20k (25%)</td>
</tr>
<tr>
<td></td>
<td>$20-35k (2)</td>
<td>$20-35k (25%)</td>
</tr>
<tr>
<td></td>
<td>$35-50k (2)</td>
<td>$35-50k (25%)</td>
</tr>
<tr>
<td></td>
<td>&gt;$80k (1)</td>
<td>&gt;$80k (12.5%)</td>
</tr>
<tr>
<td></td>
<td>Omitted (1)</td>
<td>Omitted (12.5%)</td>
</tr>
<tr>
<td><strong>Highest Level of Education</strong></td>
<td>High School Diploma (4)</td>
<td>High School Diploma (50%)</td>
</tr>
<tr>
<td></td>
<td>Some College (3)</td>
<td>Some College (37.5%)</td>
</tr>
<tr>
<td></td>
<td>Post Graduate Education (1)</td>
<td>Post Graduate Education (12.5%)</td>
</tr>
<tr>
<td><strong>Type of Caregiver</strong></td>
<td>Mother (5)</td>
<td>Mother (62.5%)</td>
</tr>
<tr>
<td></td>
<td>Father (2)</td>
<td>Father (25%)</td>
</tr>
<tr>
<td></td>
<td>Grandparent (1)</td>
<td>Grandparent (12.5%)</td>
</tr>
<tr>
<td><strong>Having been a Caregiver for a Child in an ICU Before</strong></td>
<td>Yes (2)</td>
<td>Yes (25%)</td>
</tr>
<tr>
<td></td>
<td>No (6)</td>
<td>No (75%)</td>
</tr>
</tbody>
</table>

### Patient Demographics

<table>
<thead>
<tr>
<th>Demographic Variable</th>
<th>Frequency and Percentage (Out of 6 Total Patients)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Type of Defect</strong></td>
<td>Septal or valve defect (2, 33%)</td>
</tr>
<tr>
<td></td>
<td>Transposition of the great arteries (1, 17%)</td>
</tr>
<tr>
<td></td>
<td>Single ventricle defect (1, 17%)</td>
</tr>
<tr>
<td></td>
<td>Combination of defects (2, 33%)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td>Female (5, 83%)</td>
</tr>
<tr>
<td></td>
<td>Male (1, 17%)</td>
</tr>
</tbody>
</table>
Step 5.3: Choose Appropriate Role of the Change Agent
Step 5.3: Choose Appropriate Role of the Change Agent

Results

The Palliative Care Team Assessment

Baseline Understanding of Child’s Diagnosis
- Excellent (2/8)
- Good (3/8)
- Fair (2/8)
- Omitted (1/8)

Distressful and Burdensome Child Symptoms
- Pain (4.13/5)
- Difficulty Breathing (3.38/5)
- Irritability (3.25/5)

Caregiver Support Systems
- Other Parent
- Other Family
- Friends
- Community
- Spiritual/Religious

Life Stressors
- Work
- Financial
- Family
- Physical Health
- Mental Health/Substance Abuse

Rating: Excellent, Good, Fair
Rating: Average between 1-5
Rating: Good, Fair, Absent
Rating: Absent, Present
<table>
<thead>
<tr>
<th>Expectations and Hopes for Child’s Medical Condition and Hospital Course</th>
<th>Specific Fear(s) Surrounding Child’s Medical Condition and Hospital Course</th>
</tr>
</thead>
<tbody>
<tr>
<td>“I’m hoping this surgery will fix all of her problems so she can get off the ventilator and finally get to go home with her family.”</td>
<td>“I fear the surgery won’t fix her and she will have to go through even more than she already has.”</td>
</tr>
<tr>
<td>“To not need another surgery and to get to go home.”</td>
<td>“Needing more surgeries and having to stay here longer.”</td>
</tr>
<tr>
<td>“I hope she lives as normal as possible, thrives, and doesn’t let her condition stop her”</td>
<td>“Not having a long life and being in the hospital a lot throughout her life.”</td>
</tr>
<tr>
<td>“Good recovery.”</td>
<td>“Having unexpected complications after the surgery and increase her stay.”</td>
</tr>
<tr>
<td>“That the nurses and doctors will always be readily available.”</td>
<td>“If my child isn’t cared for with 100% effort in regards to her medical condition.”</td>
</tr>
<tr>
<td>“My expectation is that my son will recover and get to come home, that his surgery will be smooth and successful.”</td>
<td>Omitted</td>
</tr>
<tr>
<td>“That my baby will recover well and be full of energy and less fussy. I just hope she feels better all around.”</td>
<td>“Having pain, being separated from her, and having delays in her growth and motor function.”</td>
</tr>
<tr>
<td>“I hope she will be healthy &amp; be able to function as normal as possible to have a happy life. I hope the hospital will be able to continue to meet her needs as she grows.”</td>
<td>“My fear is that she will be burdened by her condition and will have to spend a significant amount of time in the hospital.”</td>
</tr>
</tbody>
</table>
Results
The PSS:NICU-16 Cronbach’s Alpha Reliability Scores

<table>
<thead>
<tr>
<th>Test Category</th>
<th>Pre Test</th>
<th>Post Test</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sights and Sounds</td>
<td>.891</td>
<td>.753</td>
</tr>
<tr>
<td>Baby Looks or Behaves</td>
<td>.543</td>
<td>.950</td>
</tr>
<tr>
<td>Parent Relationship with Baby and Parental Role</td>
<td>.982</td>
<td>.868</td>
</tr>
</tbody>
</table>
Step 5.3: Choose Appropriate Role of the Change Agent

Results

The PSS:NICU-16 Subscale Scores

PSS:NICU-16 Average Scores

<table>
<thead>
<tr>
<th></th>
<th>Pre Intervention</th>
<th>Post Intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sights and Sounds</td>
<td>2.5</td>
<td>2.5</td>
</tr>
<tr>
<td>Baby Looks or Behaves</td>
<td>4.0</td>
<td>3.5</td>
</tr>
<tr>
<td>Parent Relationship with Baby and Parental Role</td>
<td>4.0</td>
<td>4.0</td>
</tr>
</tbody>
</table>

P-values:
- Sights and Sounds: P = .357
- Baby Looks or Behaves: P = .084
- Parent Relationship with Baby and Parental Role: P = .443
Limitations

- 4-week implementation time frame
- Limited number of caregivers
- Scheduling challenges between palliative care team members and caregivers
Practice Implications

This project...
- highlights the varying degrees of stressors that can negatively impact caregivers in the pediatric CICU and demonstrates how palliative care teams can promote effective coping strategies for these stressors
- cannot make conclusions that the palliative care team intervention directly increased nor decreased the varying degrees of stressors in the pediatric CICU setting
- cannot generalize its findings to other practice settings.
DISSEMINATION
Step 6: Integrate and Maintain Change in Practice

Dissemination Plan & Sustainability

Arkansas Children’s Nursing Grand Rounds on December 20th, 2022

Arkansas Children’s Research Institute Seminar on November 10th, 2022

Submit Manuscript to the Journal for Specialists in Pediatric Nursing


• Conquering CHD. (n.d.). *We exist to conquer the most common birth defects.* [https://www.conqueringchd.org](https://www.conqueringchd.org)


• Etsy. (n.d.). *Small heart lock and key/heart padlock & heart key, heart shaped lock and key.* [https://www.etsy.com/no-en/listing/225740521/small-heart-lock-and-key-heart-padlock](https://www.etsy.com/no-en/listing/225740521/small-heart-lock-and-key-heart-padlock)