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

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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

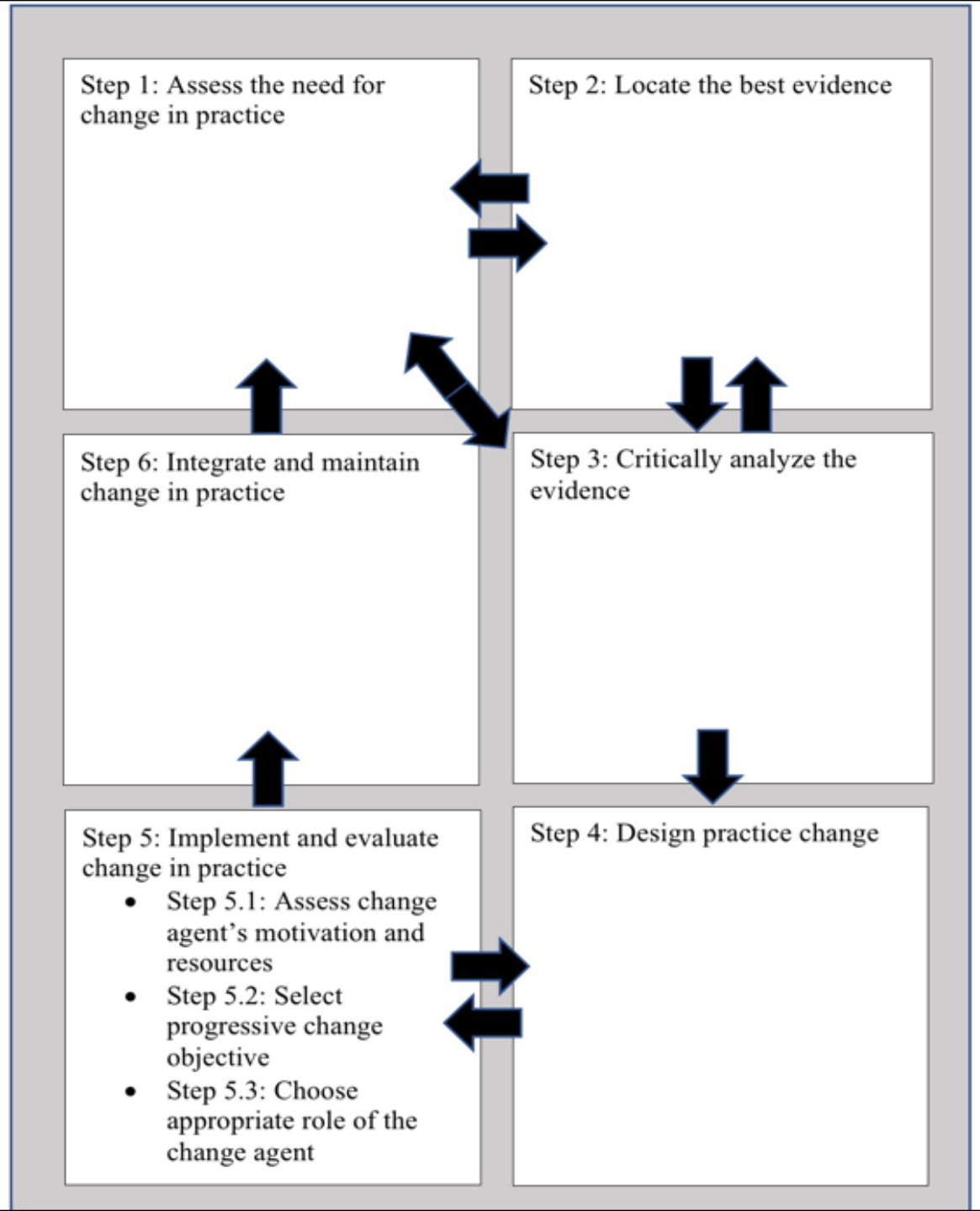
- Reduced resilience
- Slower recovery time & longer lengths of stay

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



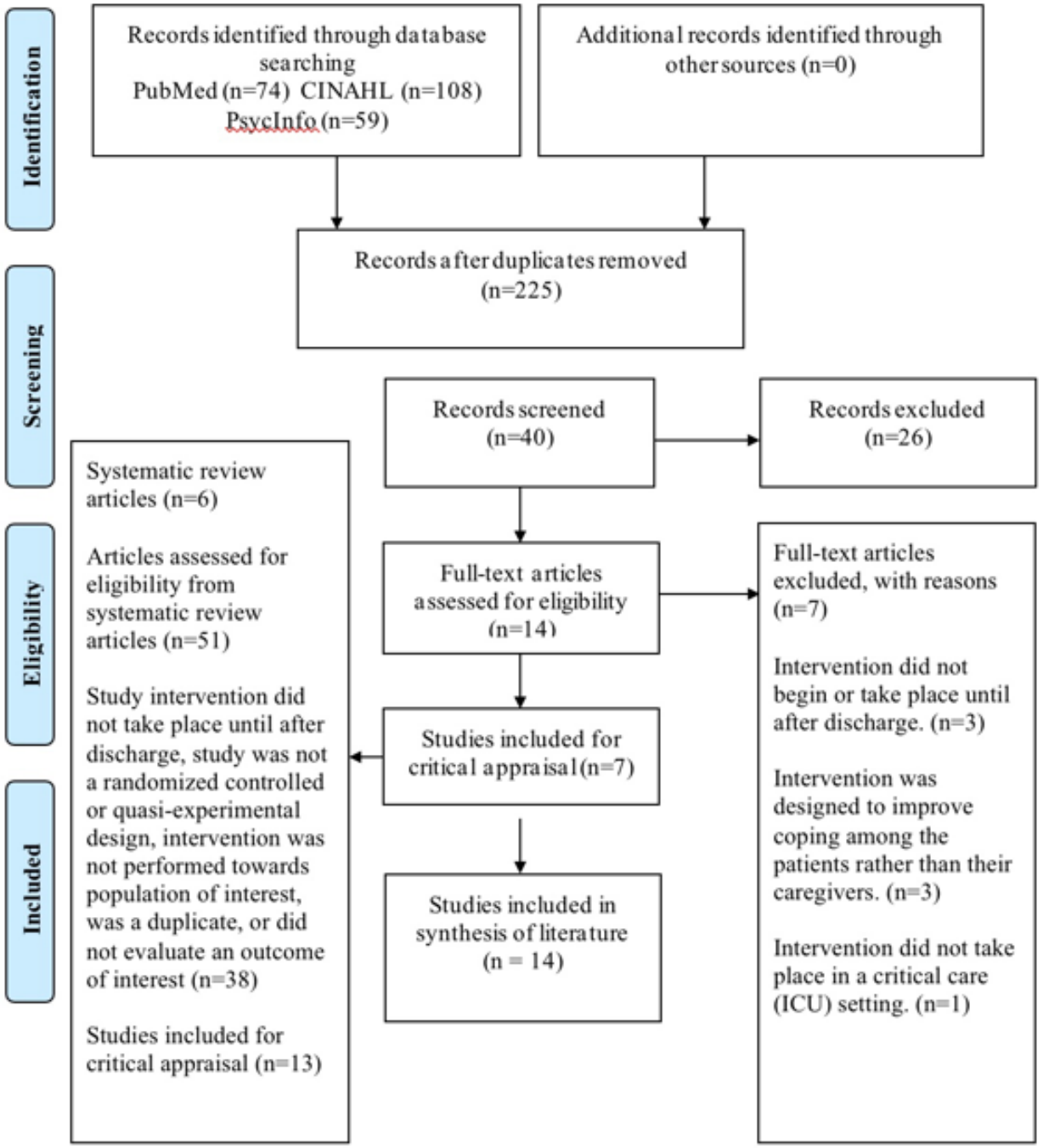
PICOT Question

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)?

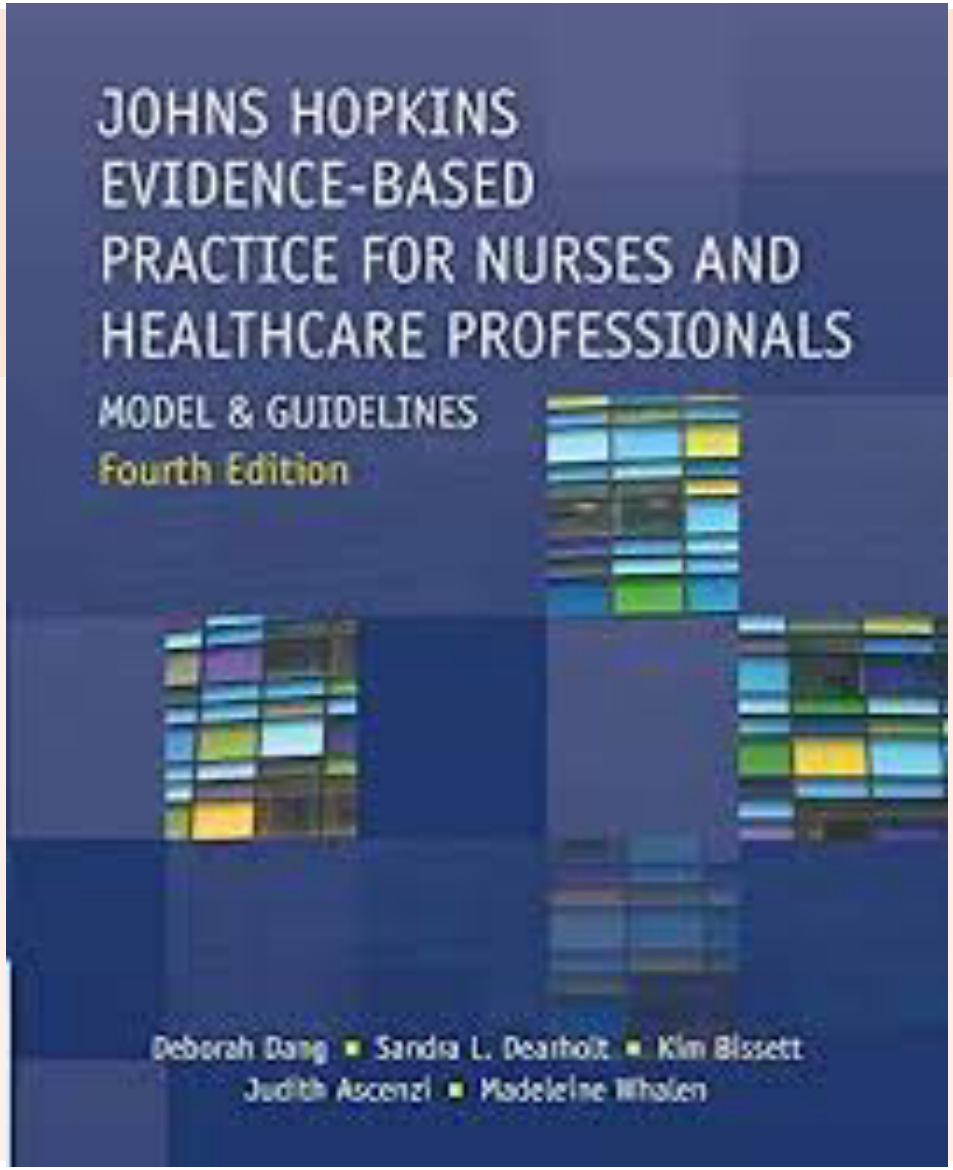
EVIDENCE

Step 2: Locate the Best Evidence

Search Strategy



Step 3: Critically Analyze the Evidence



Evidence Synthesis

Evidence Level & Quality

- Levels I-II
- Quality A/B

Evidence Synthesis

Interventions

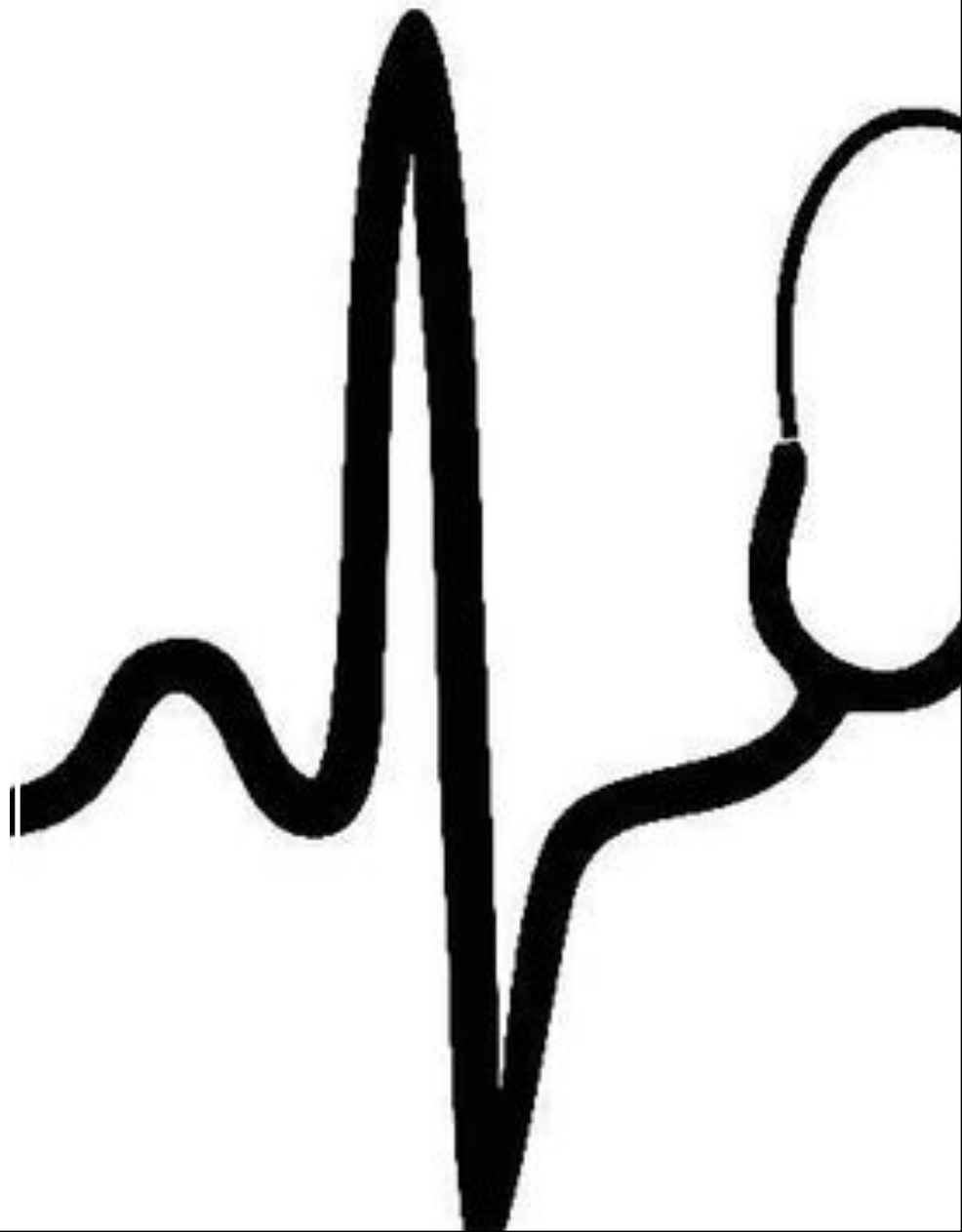
- Congenital Heart Disease Intervention Program (CHIP)
- 5 step individualized face to face program
- Mother-infant attachment program
- Early palliative care ★
- Mother-nurse partnership program
- Information sheet
- Family centered care
- Creating opportunities for parent empowerment program (COPE)
- 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

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

Washington University School of Medicine
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2018

A randomised trial of early palliative care for maternal stress in infants prenatally diagnosed with single-ventricle heart disease

Hayley S. Hancock
Children's Mercy Kansas City

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University of Michigan - Ann Arbor

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Hancock, Hayley S.; Pituch, Ken; Uzark, Karen; Bhat, Priya; Fifer, Carly; Silveira, Maria; Yu, Sunkyung; Welch, Suzanne; Donohue, Janet; Lowery, Ray; and Aiyagari, Ranjit, "A randomised trial of early palliative care for maternal stress in infants prenatally diagnosed with single-ventricle heart disease." Cardiology in the Young 28,4. 561–570. (2018).
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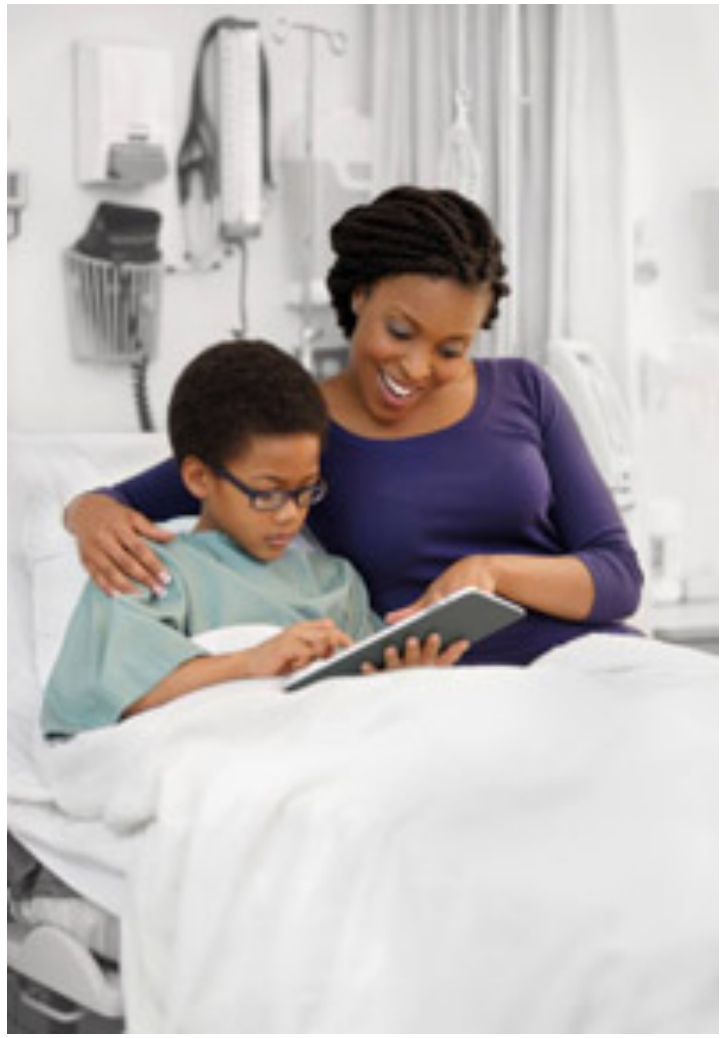
Step 4: Design Practice Change

Setting

Step 4: Design Practice Change



Patients/
Participants

Ethical Considerations

Institutional Review Board (IRB)

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

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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

Conquering CHD

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

OUTCOMES & EVALUATION

Step 5.2: Select Progressive Change Objective

PSS:NICU-16

Sights and Sounds

1. The presence of monitors and equipment
2. The constant noises of monitors and equipment
3. The sudden noises of monitor alarms
4. The other sick babies in the room

Baby Looks and Behaves

1. The unusual color of my baby
2. My baby's unusual or abnormal breathing patterns
3. My baby being fed by an intravenous line or tube
4. The limp and weak appearance of my baby
5. Jerky or restless movements of my baby
6. My baby not being able to cry like others
7. Having a machine breathe for my baby

Parental Role

1. Being separated from my baby
2. Not feeding my baby by myself
3. Not being able to care for my baby myself
4. Feeling helpless about how to help by baby during this time
5. Not having time to be alone with my bay

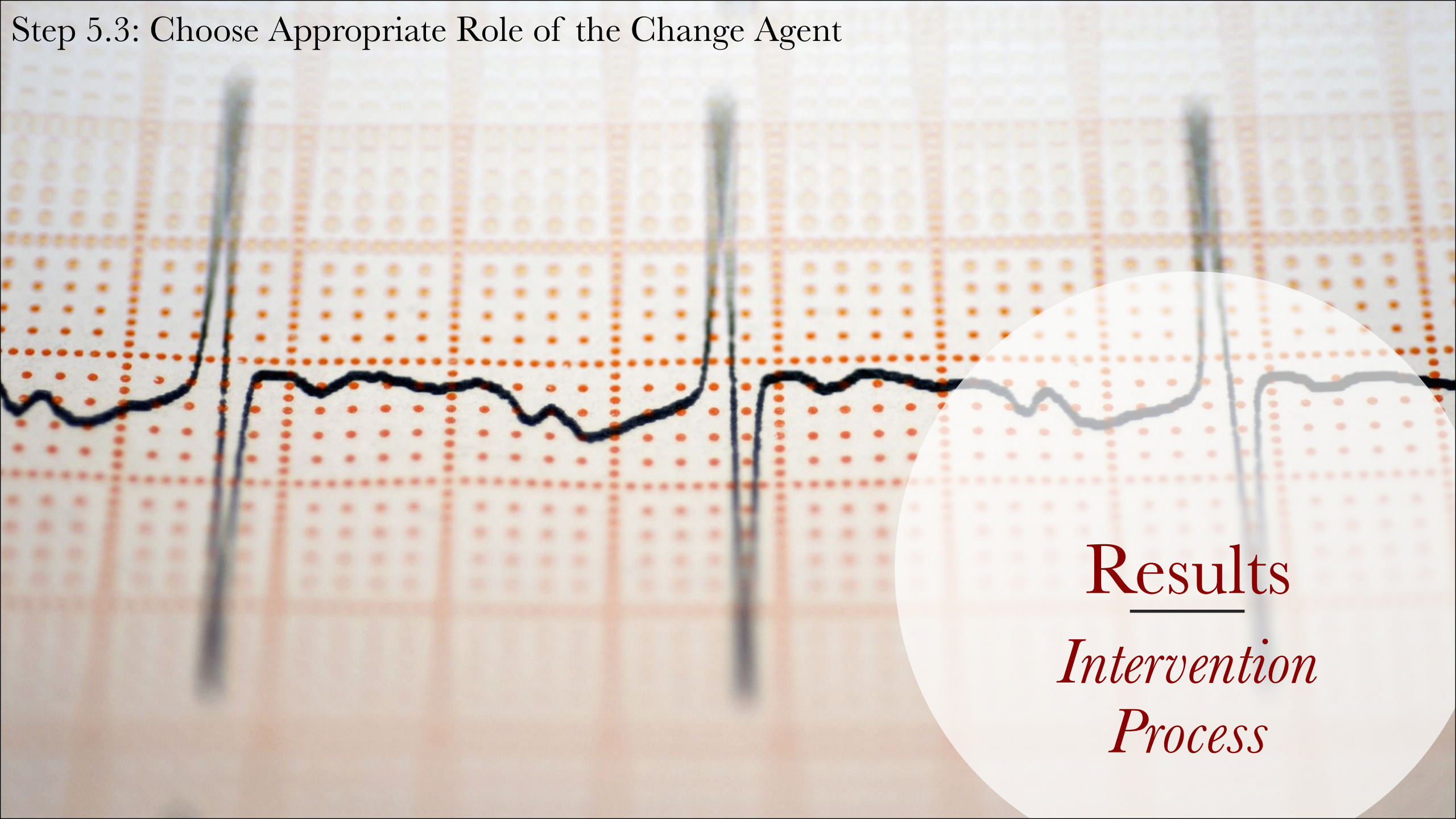
(Barr, 2017)

Caregiver Demographics

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

Patient Demographics

Demographic Variable	Frequency and Percentage (Out of 6 Total Patients)
Type of Defect	Septal or valve defect (2, 33%) Transposition of the great arteries (1, 17%) Single ventricle defect (1, 17%) Combination of defects (2, 33%)
Gender	Female (5, 83%) Male (1, 17%)



Results

Intervention Process

Results

The Palliative Care Team Assessment

Rating: Excellent, Good, Fair

- Excellent (2/8)
- Good (3/8)
- Fair (2/8)
- Omitted (1/8)

Baseline Understanding of Child's Diagnosis

Rating: Average between 1-5

- Pain (4.13/5)
- Difficulty Breathing (3.38/5)
- Irritability (3.25/5)

Distressful and Burdensome Child Symptoms

Rating: Good, Fair, Absent

- Other Parent
- Other Family
- Friends
- Community
- Spiritual/Religious

Caregiver Support Systems

Rating: Absent, Present

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

Life Stressors

Expectations and Hopes for Child's Medical Condition and Hospital Course	Specific Fear(s) Surrounding Child's Medical Condition and Hospital Course
"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."*	"I fear the surgery won't fix her and she will *have to go through even more than she already has."*
"To not need another surgery and to *get to go home."*	"Needing more surgeries and *having to stay here longer."*
"I hope she lives as normal as possible, thrives, and doesn't let her condition stop her"	"Not having a long life and *being in the hospital a lot throughout her life."*
"Good recovery."	*"Having unexpected complications after the surgery and increase her stay."*
"That the nurses and doctors will always be readily available."	"If my child isn't cared for with 100% effort in regards to her medical condition."
"My expectation is that my son will recover and *get to come home,* that his surgery will be smooth and successful."	Omitted
"That my baby will recover well and be full of energy and les fussy. I just hope she feels better all around."	"Having pain, being separated from her, and having delays in her growth and motor function."
"I hope she will be healthy &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."	"My fear is that she will be burdened by her condition and *will have to spend a significant amount of time in the hospital."*

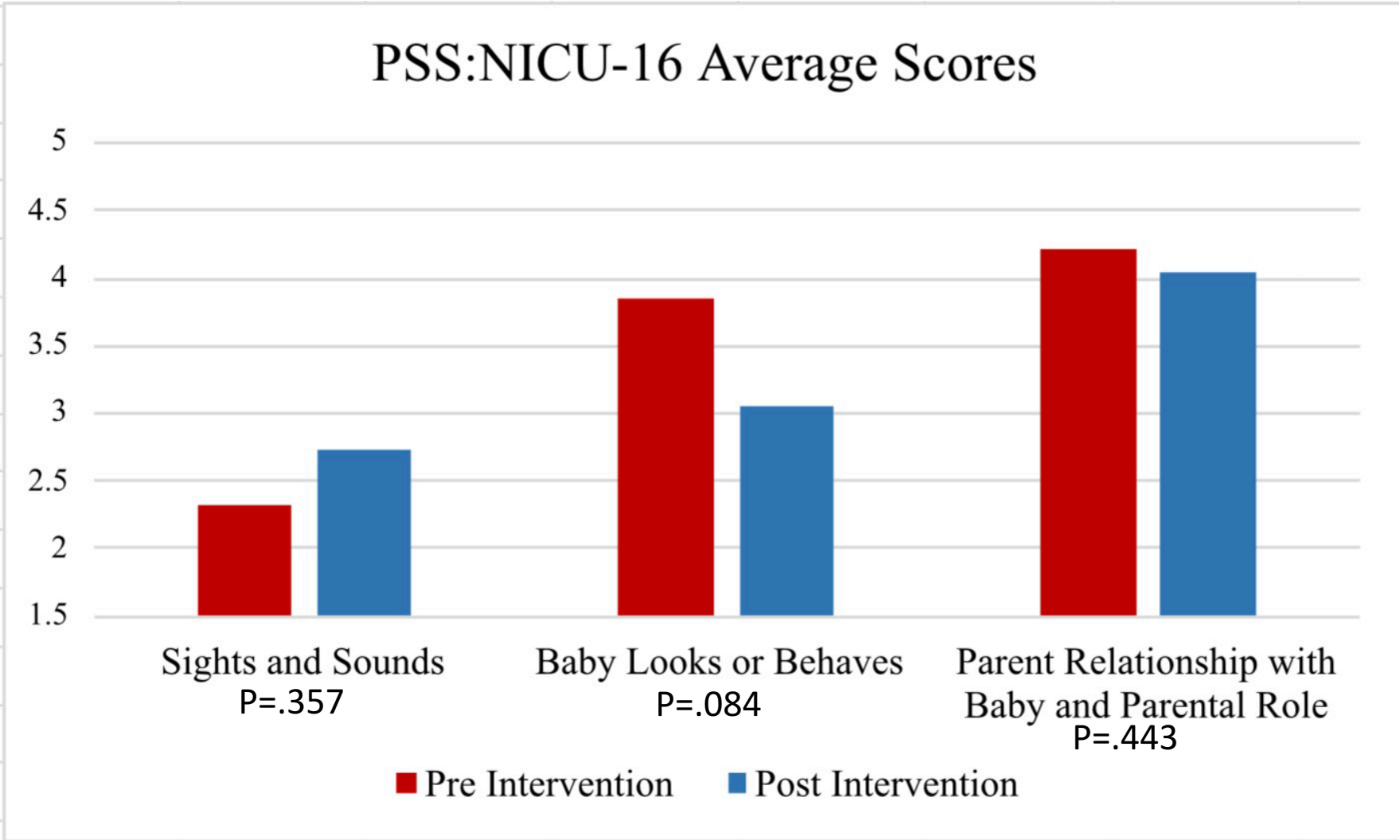
Results

The PSS:NICU-16 Cronbach's Alpha Reliability Scores

Sights and Sounds	Baby Looks or Behaves	Parent Relationship with Baby and Parental Role
Pre Test: .891	Pre Test: .543	Pre Test: .982
Post Test: .753	Post Test: .950	Post Test: .868

Results

The PSS:NICU-16 Subscale Scores



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

Practice Implications

<u>This project...</u>

- 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

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

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