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**Objectives** 

- Summarize the psychosocial burden of parents
- Describe the study context and design
- Understand how trust serves as the foundation for parent-nurse relationships
- Articulate 10 core elements to build trust with parents
- Explain common barriers to the development of trust
- Propose two concrete changes to implement on your next shift with parents



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**How many people care for MFI on Inpatient care units on a regular basis? Encounter parents of MFI within a hospital setting?**

MFI are defined as preterm and full-term infants<sup>1</sup>:

1. Have one or more life-threatening chronic medical illnesses
2. Require medical technology and care for survival
3. Are hospitalized for several weeks to months
4. Are discharged home from hospital with a chronic medical illness that requires medical technology



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**How many parents of MFI experience depressive symptoms?**

- A) 0-15%
- B) 16-30%
- C) 31-45%
- D) 46-60%

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**How many parents of MFI experience depressive symptoms?**

- National PPD rates are 12.5%<sup>2</sup>
- 25-50% of parents of infants with critical congenital heart defects<sup>3,4</sup>
- 40% of parents of preterm infants<sup>5,6</sup>



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**How many parents of MFI experience anxiety?**

- A) 0-15%
- B) 16-30%
- C) 31-45%
- D) 46-60%

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**How many parents of MFI experience anxiety?**

- National average is 11-20%<sup>7</sup>
- 42% of parents of preterm infants<sup>8</sup>
- 37% of mothers of infant with congenital heart disease<sup>9</sup>



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**How many parents of MFI experience Post Traumatic Stress Disorder/Symptoms?**

- A) 0-15%
- B) 16-30%
- C) 31-45%
- D) 46-60%

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**How many parents of MFI experience Post Traumatic Stress Disorder (PTSD)/Symptoms?**

- National average for PTSD symptoms among parents is 3-6%<sup>10</sup>
- 67.5% of parents of infants with gastrointestinal surgery experience posttraumatic stress symptoms<sup>11</sup>
- 83% of parents of infants with hypoplastic left heart syndrome when in the PICU<sup>12</sup>

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**How many parents of MFI experience Post Traumatic Stress Disorder/Symptoms?**

- 79% of parents of infants with congenital heart disease<sup>13</sup>
- 30% of parents of high-risk infants admitted to the NICU<sup>14</sup>



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**Background**



- MFI population is increasing due to advances in medical technology<sup>15</sup>
- Parents endure multiple stressors and struggle with their mental health<sup>16,17</sup>
- Parents and MFI are at risk of sub-optimal parent-infant interactions, placing them at risk for altered-outcomes - DOUBLE JEOPARDY <sup>18</sup>



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## Background



- Nurses are well-positioned to offer parents psychosocial support<sup>16,17</sup>
- This happens within supportive parent-nurse relationships<sup>19</sup>
  - Decreases parents' stress and concerns<sup>20</sup>
  - Support for their mental health<sup>21</sup>
  - Lowered anxiety and depression<sup>22</sup>
  - Increased parenting confidence<sup>23</sup>



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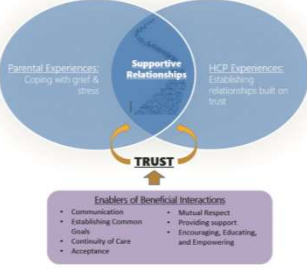
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## Grounded Theory



- Trust is the foundation of parent-nurse relationships<sup>24</sup>
- Trust is "assured reliance on the character, ability, strength, or truth of someone of something"<sup>25</sup>
- This became evident in the grounded theory: "Journeying Alongside One Another"<sup>17</sup>



**Parental Experiences:** Coping with grief & stress

**Supportive Relationships**

**HCP Experiences:** Establishing relationships built on trust

**TRUST**

**Enablers of Beneficial Interactions**

- Communication
- Establishing Common Goals
- Continuity of Care
- Acceptance
- Mutual Respect
- Providing support
- Encouraging, Educating, and Empowering

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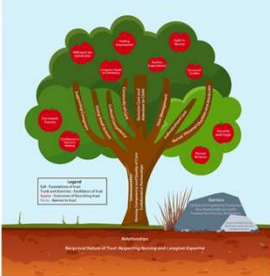
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## Scoping Review on Trust<sup>26</sup>



- Explored trust development between pediatric nurses and children/caregivers
- Systematic search of 6 databases yielding 81 studies
- Findings:
  - Trust is bi-directional
  - Communication was most important
  - Trust takes time

*Trust is essential for safe, high-quality pediatric nursing care and requires intentional approaches*



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## Study Overview

Qualitative Interpretive Description Study<sup>27</sup>

- Interpretive Description: helps understand contextual human experiences to inform practice
- 15 1:1 or 1:2 interviews with parents of MFI during their admission to the Alberta Children's Hospital inpatient care units
- Semi-structured interview guide
  - MFI defined as:
    - One or more chronic condition
    - Reliance on medical technology for survival
    - >30 admission to hospital
    - Discharge home with a chronic illness



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## Findings: Parent Characteristics

Parent participants

- 18 parents
  - Age: 28-57
  - 13 mothers, 4 fathers, 1 grandmother
  - Diverse backgrounds
    - 11 White European
    - 5 Southeast Asian
    - 1 Black/African/Caribbean
    - 1 Preferred not to say
  - Education levels
    - Some high school = 1
    - Highschool = 1
    - Some college/university = 3
    - Bachelors' degree = 10
    - Graduate degree = 3
  - Marriage
    - Married = 14
    - Single = 3
    - Divorced = 1



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## Findings: Infant Characteristics

Medically Fragile Infants

- 15 infants: 7 male and 8 female
  - Age: 2 months - 11 months

Infants' primary and secondary diagnoses.

Primary Diagnoses	Secondary Diagnoses
Chronic Lung Disease	Feeding Issues
Chronic Heart Disease	Pulmonary Hypertension
Congenital Diaphragmatic Hernia	Trisomy 21
TGA	Congenital Diaphragmatic Hernia
Pulmonary Hypertension with ASD	Clubbed Feet
MIRAGE Syndrome	Double Urterer
Wolf-Hirschhorn Syndrome	Adrenal Insufficiency
Premature	Heart Defect
Intestinal Malrotation	Grade 3 Kidney Reflux
Trisomy 21, Pulmonary Hypertension	Cleft Lip
Laryngomalacia	Surgical NEC
Myotonic Dystrophy	Bronchopulmonary Complications
AVSD/Tetralogy of fallot	Hydrops
NEC	Chronic Lung Disease
CHARGE syndrome	

Infants' type of medical technology dependency.

Technology	Number of Infants
Feeding (gastrostomy (G) tube, jejunostomy (J) tube, gastrojejunostomy (GJ) tube, nasogastric (NG) tube, nasojejunal (NJ))	12
GI (ostomy, colostomy, ileostomy)	1
Vascular (central line, IVAD, browiac, PICC)	3
Respiratory (oxygen, suction, BiPAP, CPAP, ventilation, tracheostomy)	8

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**Findings: Themes** 

- From Hardship to Collaborative Partnerships
- Parents' Description of Trust within Parent-Nurse Relationships
- Core Elements to the Development of Trust
- Disruptions to the Development of Trust



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**From Hardship to Collaborative Partnerships** 

- Parental Experiences:
  - Roller coaster of emotions
  - Constant anxiety and fear
  - Feelings of guilt and failure
  - Loss of control
  - Trauma from witnessing painful procedures and not being able to protect their infant
- This created a need for parents to be supported, which was offered via trusting nurse-parent relationships



*"So one bad experience like that wa a lot of blood work and traumatic for use to have to watch her get, like screening, you know" (TR31)*

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**From Hardship to Collaborative Partnerships** 

Trusting parent-nurse relationships: The foundation of collaborative partnership

- Parent-nurse relationships were mutually dependent
- Trust was formed within the interactional space
- Deeply intimate relationships



*"We didn't know anything about our nurse or whether we trusted her or not, but she really took the time to get to know us and we got to know her. And then we trusted her because we built that relationship" (TR34)*

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### Parents Description of Trust



- Belief that nurses have infant and parents' best interest at heart
- Confidence in receiving high-quality and safe care
- Mutual respect that gives peace of mind
- Environment for open and honest communication
- Being listened to without judgement
- Synonyms: accountable, reliable, reassurance, available, attentive, and dependable



*"Trust comes from a bunch of things like accountability, reliability, comfort, and then the communication, and all those things actually make trust trust" (TR30)*

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### 10 Core Elements to the Development of Trust



1. Took time to get to know the infant
  - Genuine interest and care for the infant
  - Take time to read the infants' chart
2. Empowered parents through teaching, educating, and explaining
  - Demonstrate and teach how to provide basic and medical care
  - Made them feel capable and confident



*"I definitely appreciated the nurses who would either ask questions about things that she liked or would read the infants chart, it was nice that we noticed they were being attentive to those things" (TR23)*

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### 10 Core Elements to the Development of Trust



3. Nurses' experience and expertise
  - Trustworthy nurses had knowledge, competence, and expertise
  - Gave parents confidence to take breaks
  - Nurses who asked recognized their limitations
4. Attentive and Responsive
  - Nurses who stopped to check in
  - Timely response to monitors and call bells
  - Took time to settle the infant
  - Followed through and loved their job



*"There's just the individuals who do go above and beyond and it's really in their soul, but you can't necessarily train that into an individual" (TR11)*

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### 10 Core Elements to the Development of Trust



- 5. Caring attitude
  - Demonstrated kindness and compassion
  - Empathetic to the parents' difficulties
  - Acknowledged parents' emotional struggles, fears, and stress
- 6. Involved parents in care and decision making
  - Ask parents about their care preferences
  - Included in decision making
  - Encourage parents to care for their infant



*"I sometimes feel uncomfortable when they just come in and start doing stuff with her, and then my antenna goes up right away" (TR30)*

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### 10 Core Elements to the Development of Trust



- 7. Cared for parents
  - Care for parents' well-being
  - Encouraged parents to take breaks
  - Recognized when parents struggled with emotions
- 8. Open and Honest Communication
  - Communication even when busy
  - Key to building relationships
  - Introduced self
  - Listen



*"Communication is really important and just taking the time like even though it's a lot, even though it's hard as a nurse because you feel like you have a million things in your brain, but taking that time is going to build trust every time" (TR12)*

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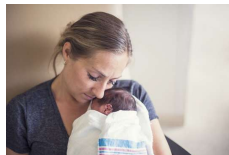
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### 10 Core Elements to the Development of Trust



- 9. Primary Nursing
  - Inconsistent nursing thwarted trust
  - Consistent nursing helped build trust because the nurse knew the parent and infant
- 10. Faith
  - Only 1 mother spoke to this
  - Regularly prayed and trusted God



*"Sometimes I know there will be lapses somewhere, but then I just trust God. Whoever will be the nurse taking care of my baby, I will say, Father, use the nurse very well to hand or service the care to him" (TR26)*

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## Disruptions to the Development of Trust



- If the Core elements were missing
- Medical Mistakes
  - If nurses were open and honest, and apologized, trust could be re-established
- Moving Units
  - Transitioning units was stressful (from the NICU or PICU)
  - Change from 1:1 nursing to 1:3
  - Increased parents' fear of infants' safety



*"If you are transparent. If it is clear what the mistake was or why there was distrust and that is spoken about, if you talk to the person, it should be good. But if it gets pushed away, you feel not heard, I think they get mistrust" (TR2)*

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## Pathway to Success



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## Why this matters: The Science



- Hospital environment is full of toxic stress
  - Constant noise, lights, stimulation
  - Multiple painful procedures
  - Sleep disturbances
  - Inconsistent caregiver
- Parents Mental Health Struggles = Additional Risk
  - Compromised parent-infant interactions
  - Poor neurodevelopmental outcomes
  - Embedded negative experiences in infant biology (epigenetics, DNA methylation, shortened telomere length)
- Trust Based Relationships = parents receive psychosocial care = MFI buffered from toxic stress! = improved neurodevelopmental outcomes



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### What this means for you



- Use the 10 core elements
- Recognize trust is the foundation to family-centered care
- Prioritize trust-building relationships – its not extra – its essential!
- System changes
  - Primary nursing models where possible
  - Education on trust building for students and staff
- QUESTION TO LEAVE YOU WITH: What are 2 changes you can incorporate into your practice?



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### Questions!



### References:



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