

Experiences and Care Needs of Parents whose Children are born with Congenital Heart Disease

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Disclosure Statement

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Objectives

1. Describe the key findings of the literature regarding families of children with congenital heart disease for the past 15 years from 2000 to 2015.
2. Verbalize understanding of parents' experiences as their child with congenital heart disease went through heart surgery.
3. Identify communication strategies to help ensure effective teamwork and patient safety.

Why did I become interested in parents' experiences and care needs?

Clinical Practice

A review of literature was conducted about families of children with congenital heart disease published in the past 15 years.

Findings

- Ninety-four articles were reviewed.
- These articles were written by different disciplines, such as medicine, nursing, psychology, public health, and others, from 21 countries.
- Four major themes were derived from the articles.

Four Major Themes

- Impacts on parents' psychological health;
- Impacts on family life;
- Parenting challenges; and
- Family-focused interventions.

Gaps and Research Needs

- Lack of studies on
 - Parents' overall experiences when having a child with CHD; and
 - Parents' perceptions of healthcare providers' actions during parent-provider encounters.

To answer the first gap, a phenomenological study was conducted to explore parents' overall experiences.

Participants

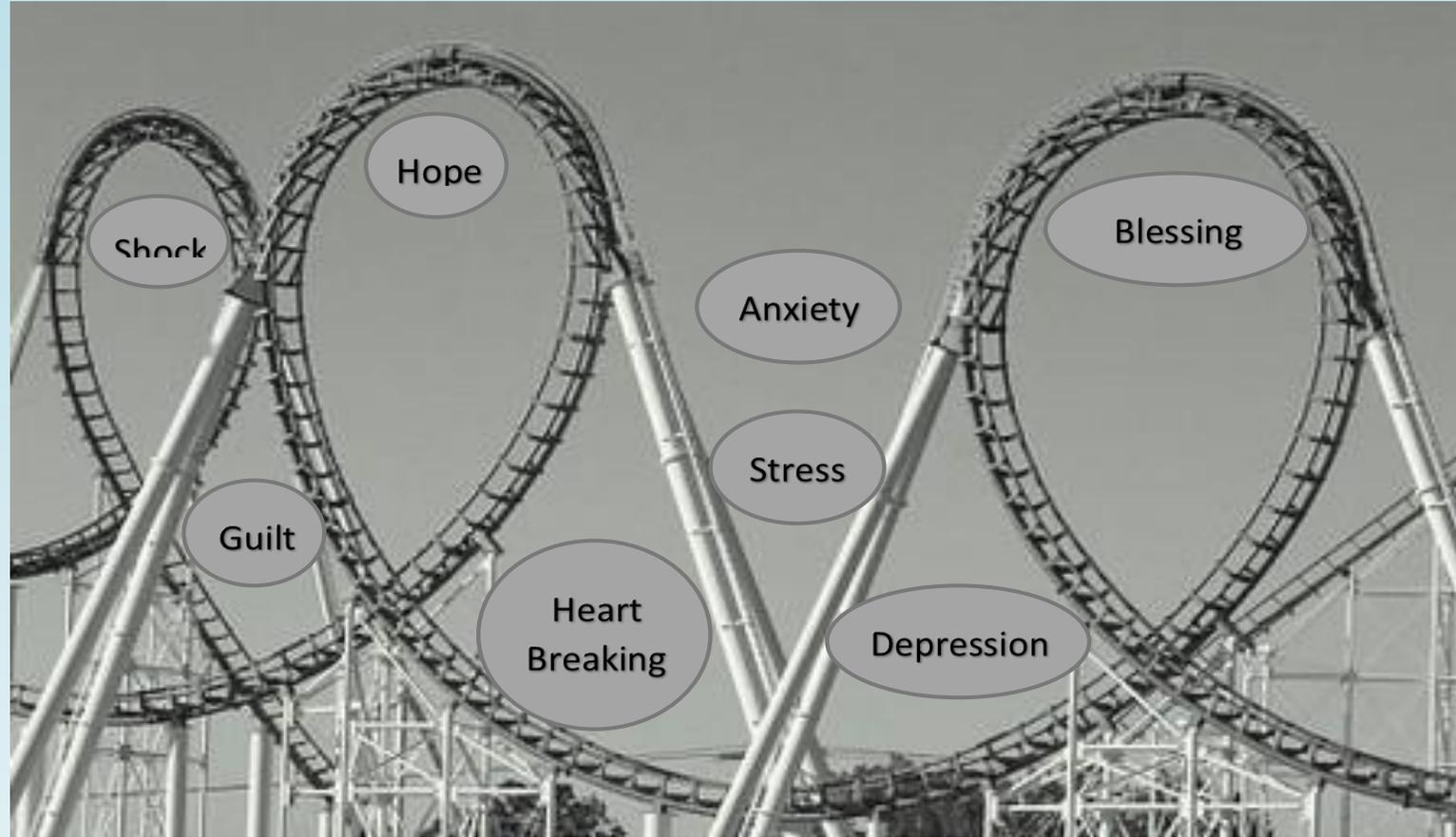
- Twenty-one interviews from 13 parents, 10 mothers and 3 fathers;
- Aged between 19 and 41 years old;
- Married ($n = 4$), single but lived together ($n = 5$), and single ($n = 1$);
- White ($n = 6$), Non-Hispanic Black ($n = 5$), and Hispanic ($n = 2$);
- Education ranged from less than high school to college graduates;
- Family income ranged from \$20,000 to \$80,000.

Demographics of the Children

- 10 children, 9 boys and 1 girl;
- Between 10 weeks and 5 years old;
- Heart defects:
 - Atrial Septal Defects ($n = 1$),
 - Ventricular Septal Defects ($n = 4$),
 - Atrial/Ventricular Septal Defects ($n = 1$),
 - Tetralogy of Fallot ($n = 3$), and
 - Pulmonary Stenosis ($n = 1$).

Parents' Overall Experiences

An Emotional Rollercoaster



Expecting an uneventful pregnancy before the diagnosis

- “I thought if I had kids, they would be healthy with no problems.”
- “Once I had two healthy children, I thought this time would be just like last times. I would have a baby and go home. Everything would be fine.”

It was a shock to know the child's heart defect

- “It was a shock. My heart was breaking. Our whole world changed.”
- “It was the most devastating thing I had ever heard in my life. When they told me, I was shocked. At that moment, I felt like I stepped onto a roller-coaster.”

What did I do that caused it?

- “What did I do that caused it? What didn’t I do? Why?”
- “I felt like it was something that I did wrong during the pregnancy or I wasn’t careful. What did I do to have my child have this heart problem?”

Hoping the child's heart defect will fix itself

- “He’ll beat the odds and won’t need surgery. The heart defect will fix itself on its own. I’ll go in one day and they’ll go: oh everything is fine.”
- “I was holding her and looking at her in the clinic. I was like ok, any time now they’ll be here and tell me your heart is fine and we can go home.”

Dilemmas in making decisions for heart surgery

- “The heart defect has to be taken care of. It is basically what keeps you alive. . . . But this is the HEART. It’s a heart surgery. It’s like the devil and the angel on each shoulder.”
- “I don’t want him to go through heart surgery. But, I can not be selfish. I have to think of the outcome. The surgery will help him, and make him a stronger and healthier boy.”

Unable to let my child leave my arms and be given to the surgical staff

- “He’s my baby. If I were to let him go, he wouldn’t be mine anymore. I couldn’t let him be out of my arm. I just couldn’t hand my baby over.”
- “I didn’t want him to go. This could really be the last time we saw him. I felt like I had lost a part of me. I had just watched a chunk of my heart get taken away.”

Sitting on pins and needles during child's surgery

- “I felt like I was sitting on pins and needles when he was in surgery.”
- “Every time we saw a doctor walk by, it was like [gasp]. My heart leaped out of my chest. Towards the end, that adrenaline rush. I was just going up and down and up and down.”

Like receiving a new born baby after surgery is done

- “When the surgeon said that everything went fine, it was like having a newborn baby again. It was like being in the hospital and the doctor handed me the baby. It was a surreal feeling.”
- “We were all so happy. I hugged Dr. [the surgeon’s name]. He gave our son a new chance, new life.”

Heartbreaking to see my child the first time after surgery

- “Seeing him surrounded with lots of machines was difficult for me. I started to cry because I have never seen a three month old baby surrounded with so many people and machines.”
- “I went back to see him. When I first went in, all I could see were machines, tubes, and people in the room. When I saw my baby, I couldn’t do it. I couldn’t see him having tubes everywhere, and being not responsive. I broke down and turned back around.”

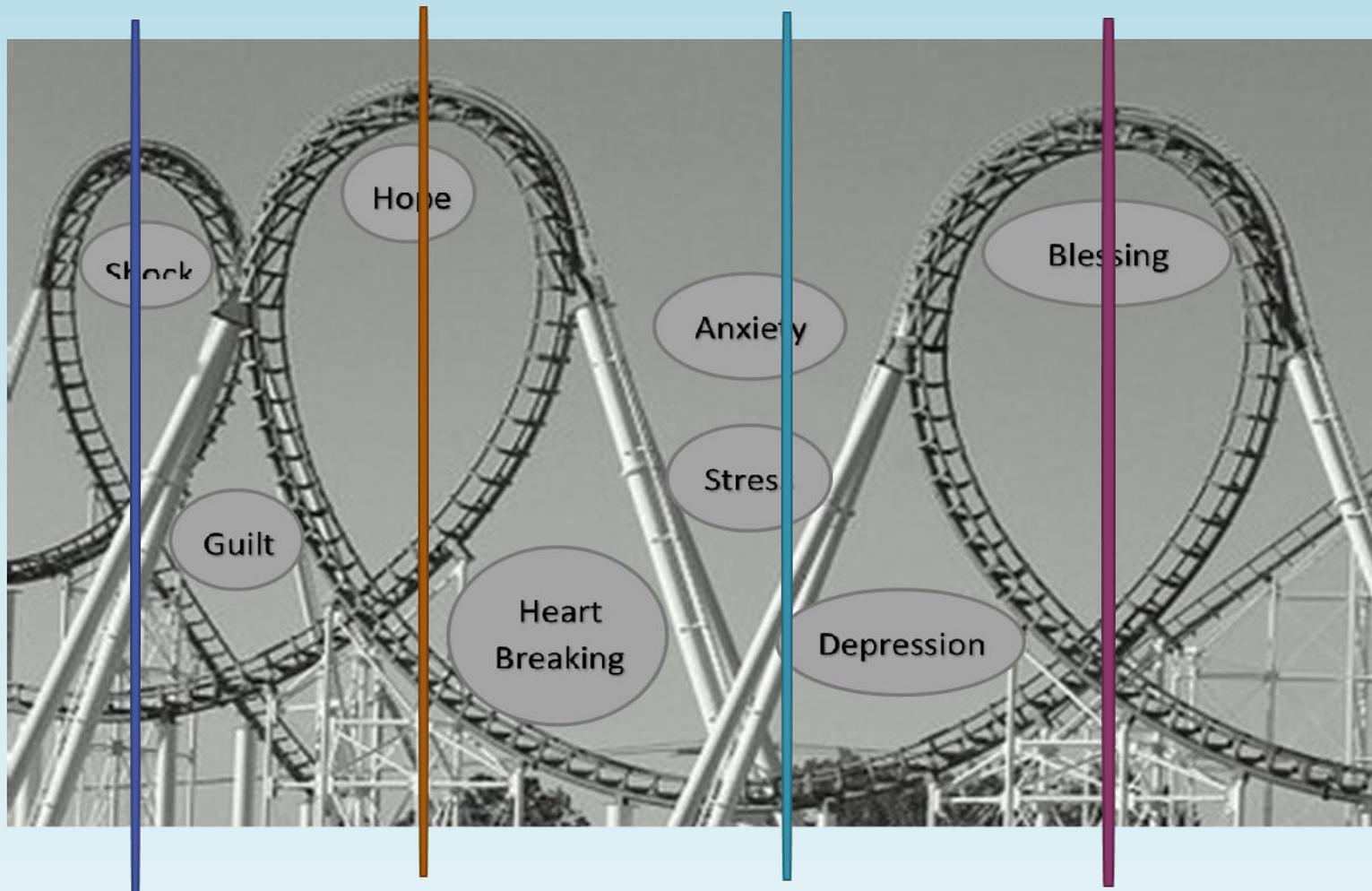
Feeling relieved when transferred to a cardiac unit

- “A relief is that we could all be in the room together and he could see his brothers and his brothers could see him too and be there to know that he’s ok.”
- “I was happy he was coming to a cardiac unit. I was just excited that it was a closer step to going home. I felt I was stepping out of the rollercoaster.”

It was a blessing for our family

- “Blessed. I’d rather have him not to have this, but I also feel that him having this condition has brought us a lot closer.”
- “There were so many blessings out of that pain. It just strengthened us, our family, and our faith. I would never choose to do it again, but I wouldn’t change anything about it. It was a blessing.”

Summarize Parents' Experiences



Parents' critical moments/vulnerable times

- When parents
 - Received their child's diagnosis;
 - Were informed that their child had to have heart surgery;
 - Handed their child over to the surgical staff;
 - Waited during surgery; and
 - Saw their child for the first time in PICU after surgery.

Associated Stressors

- The uncertainty of the outcomes of the surgery;
- The loss of parental control;
- The anxiety of the technical environment of the intensive care unit; and
- The fear of their child's physical appearance after surgery.

To response to the second gap, a directed content analysis was conducted to study parents' perceptions of healthcare providers' actions.

Conceptual Framework

- Swanson Caring Theory
 - A middle-ranged theory that defines caring and caring process;
 - Empirically derived through three phenomenological studies related to perinatal loss.
 - According to the theory, there are five caring processes:
knowing, being with, doing for, enabling, and maintaining belief.
- These processes reflect a holistic approach to meet patients' and families' physical, psychological, and spiritual needs.

Parents' Perceptions of Providers' Actions

Knowing:

- Providers – Striving to understand parents' situations and experiences.
- Parents – Feeling understood.

Being with:

- Providers – Accompanying parents through difficult times physically, emotionally, and spiritually.
- Parents – Feeling attended to.

Doing for:

- Providers – Anticipating the things parents would do for themselves if they were able to.
- Parents – Feeling helped.

Enabling:

- Providers – Guiding parents to participate and maintain their parenting role at difficult times.
- Parents – Feeling confident.

Maintaining belief

- Providers – Believing that parents will get through their child's surgery and face a future with a positive meaning if supported.
- Parents – Feeling hopeful.

Strategies to Ensure Teamwork and Patient Safety

- Help one another to care for patients and families;
- Be empathetic, instead of being sympathetic;
- Avoid talking and joking about non-patient related topics among providers in patients' rooms; and
- Pay attention to things that parents felt important, such as beeping monitors.

Actions that were considered as caring by parents

- “Wanted to know my son’s routine so that they could continue them in the hospital.”
- “Talked to me as if they understood what I was going through.”
- “Stayed right there with us when we did not know what to do with my son’s diagnosis.”
- “Made me feel that “yeah I can do this. I can get through this traumatic situation.”
- “Changed my son’s diaper to let us, the tired parents, sleep in the middle of night.”
- “Came in with a smile and interacted with my son before jumping into things.”
- “Made us feel there’s nothing our son could not do.”
- “Worked as a team was what helped me the most.”
- “Not only cared about the patient, but also took care of the family.”

Conclusion

1. The key findings of the literature regarding families of children with congenital heart disease for the past 15 years.
2. Parents' experiences as their child with congenital heart disease went through heart surgery.
3. Strategies to help ensure effective teamwork and patient safety.

Clinical Practice, Theory, and Research: A Circular Movement



Clinical Implications: Parents' Perspectives



So, who are we?

- We are healthcare teams.
- We are nurses, physicians, dietary workers, clerks, housekeeping, nursing assistants, and volunteers.
- We are everyone whom patients, families, and visitors encounter in the hospital.

Thank you!



Questions?

