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Parents' perceptions of healthcare providers' caring: Nothing is too small for parents and children with congenital heart disease hospitalized for heart surgery

Holly Wei, PhD, RN, CPN [a,*], Cecelia I. Roscigno, PhD, RN, CNRN [b], Kristen M. Swanson, PhD, RN, FAAN [c]

[a] College of Nursing at East Carolina University, Greenville, NC, USA
[b] School of Nursing at University of North Carolina, Chapel Hill, NC, USA
[c] College of Nursing, Seattle University, Seattle, WA, USA

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ABSTRACT

Background: Parents of children with congenial heart disease (CHD) face frequent healthcare encounters due to their child's care trajectory. With an emphasis on assuring caring in healthcare, it is necessary to understand parents' perceptions of healthcare providers' actions when their child undergoes heart surgery.

Objectives: To describe parents' perceptions of healthcare providers' actions when their child is diagnosed with CHD and undergoes heart surgery.

Methods: This is a qualitative study with in-depth interviews. Parents of children with CHD were interviewed twice after surgery. We analyzed data using directed content analysis guided by Swanson Caring Theory.

Results: Findings of the study indicate that parents perceive caring when providers seek to understand them (*knowing*); accompany them physically and emotionally (*being with*); help them (*doing for*); support them to be the best parents they can be (*enabling*); and trust them to care for their child (*maintaining belief*).

Conclusions: Healthcare providers play an irreplaceable role in alleviating parents' emotional toll when their child undergoes cardiac surgery. Providers' caring is an integral component in healthcare.

Introduction

Caring is the foundation for human connections and relationships.[1–3] Yet, discordance exists among economics, practice and caring because the prevailing operations of healthcare are largely driven by economics, science, and technology.[2] Healthcare institutions are oftentimes off-base in their readiness to address "what it means to be human, to be vulnerable, to be ill, to be cured, to be cared for, to be healthy, and to be healed".[2(p.87)] Resolution to this discord lies in adopting an ethic of human caring as an essential underpinning for healthcare.[1–5]

In the United States, healthcare has been undergoing reformation. Patients' and families' experiences are quality of care indicators,[6] which is associated with organizations' economic well-being.[7] On the website of the Centers for Medicare & Medicaid Services, consumers can compare hospitals based on patients' experiences as measured by the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) survey.[8] Likewise, achieving Magnet® designation is another indicator for consumers that those designated hospitals provide excellent care and demonstrate high nurse and patient satisfaction.[9]

To understand consumers' experiences in healthcare, it is necessary to examine their perceptions of healthcare providers' actions. In this article, we explored providers' caring behaviors through the perceptions of parents of children with congenital heart disease (CHD) undergoing heart surgery. CHD is a prevalent birth defect and a leading cause of birth-defect associated death

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* Corresponding author. College of Nursing at East Carolina University, Greenville, NC 27858-4353, USA.
E-mail address: weih16@ecu.edu (H. Wei).

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among children.[10–12] More than 40,000 children in the United States are born with CHD every year, with an incidence rate of 8–10 per 1000 live births.[10–12]

From the moment when parents are informed about their child's diagnosis of CHD, they start to experience roller-coaster like emotions.[13] Children with CHD require ongoing medical or surgical treatment.[10,14] When children are hospitalized for heart surgery, parents report high levels of stress throughout their hospital stay.[15,16] Literature shows that having a child with CHD affects parents' psychological health, their family life, and their parenting roles.[16] However, what is lacking in the literature is research addressing parents' interpersonal experiences with healthcare providers when their child is diagnosed with CHD and undergoes heart surgery.

Healthcare providers such as physicians and nurses are in a position that can create or mitigate patients' and parents' pain and stress. Depending on the extent to which providers understand and handle their expectations and needs, healthcare providers could either produce parents' agony or prompt their respite.[17,18] Therefore, the purpose of this article is to describe parents' perceptions of healthcare providers' actions when their child is diagnosed with CHD and undergoes corrective heart surgery.

Methods

Design

This is a qualitative study with in-depth interviews.

Human subjects

Institutional Review Board of the affiliated institution had approved the study before it was initiated. We had obtained parents' informed consent before our data collection.

Setting

This study took place in an academic healthcare center on the east coast of the United States. This hospital is one of the children's heart centers in the state.

Sample

Parents of children with CHD undergoing heart surgery participated in the study. Inclusion criteria were that parents had to a) be at least 18 years of age of any socioeconomic backgrounds, b) speak and read English, and c) be undergoing their child's first heart surgery. Exclusion criteria were that parents would be excluded if they a) were not willing to share their experiences, or b) could not communicate because of intellectual or language impairments.

Sample size

The exact sample size for qualitative studies is hard to predict beforehand.[19–21] Therefore, we used informational saturation[21] to help determine the sample size. Recruitment continued until informational saturation was achieved, which was when themes had been repeating in interviews even with a group of parents who were socioeconomically diverse.

Recruitment

We recruited a convenience sample[22] of parents on a children's cardiac unit between July and December 2014. We chose this unit because children would recover from their heart surgery on this unit till they went home. To make the study known, information flyers were posted on the unit. The information on the flyers included the title of the study, *Parents' Experiences and Expectations of Care when Their Children with Congenital Heart Disease Undergo Heart Surgery*, contact information of researchers, and descriptions to assure parents that contacting researchers would not obligate them to participate in the study, but help them learn more about the study so that they could make an informed decision as to whether this study would be right for them. The first author was a nurse on the unit at the time; yet, she had not initially contacted any parents until they expressed interests in knowing more about the study.

When parents saw the flyers on the unit and were interested in knowing more about the study, they could either call the number on the flyer or tell the nurse who was taking care of them at the time that they would like more information about the study. After being contacted, the first author would then talk to the parents and make face-to-face appointments to introduce herself, describe the study, and answer their questions. If parents agreed to participate, the first author would complete the process of obtaining parents' informed consent and set up a time and place for the first interview. The study required one parent per family; but both parents were welcome. When both parents participated, they were interviewed separately for their privacy and individual input. To protect parents' privacy, no other providers, except the first author, knew which parents had agreed to participate in the study. The first author assured parents that under no circumstances would their child's care be affected whether they agreed or declined to participate.

Data collection

We collected data using in-depth open-ended interviews at two time-points, one week after surgery and 4–6 weeks after surgery. The in-depth open-ended interviews helped us gain a deep understanding of parents' expectations of care when their child was diagnosed with CHD and underwent heart surgery. The first interview occurred in-person in the hospital and the second interview took place in-person or on the phone after the child was discharged to home.

The time and location of the interviews were selected based on parents' preferences. As to the time of the first interviews, parents preferred a time when another family member could sit with the child in the hospital room so that the child would not be left alone. For the location, the first interviews took place in a private setting of the hospital, such as patients' consultation room on the unit, which is a private room with a sofa and a door that is soundproof to assure parents' comfort and privacy. No other providers, except the first author, knew about the interviews.

The first author conducted both interviews. The interviewer (the first author) reassured parents that all their information would be kept confidential. Being a nurse on the unit, the first author was able to build a great rapport with parents, which helped parents open up during their interviews and share the details of their experiences and appraisals. Parents were aware that the interviews were being recorded via a digital voice recorder.

During the interviews, grand tour questions were used to encourage parents to open up about their experiences and probing questions were used to help them answer the questions as queried to ensure that optimal responses were obtained from parents.[19,23] To address parents' perceptions of healthcare providers' caring actions, the grand tour question of the first interview was "What kind of actions by [nurses, physicians, or other personnel] were caring to you?" and "Looking back, what kind of actions by [nurses, physicians, or other personnel] were caring to you?" for the second interview. Probing questions were asked such as "How did that make you feel?", "Why was that important?", and "Help me understand why you thought that way".