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Healthcare providers' caring: Nothing is too small for parents and children 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 congenital 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.

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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}

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* Corresponding author. College of Nursing at East Carolina University, Greenville, NC 27858-4353, USA.

E-mail address: wei16@ecu.edu (H. Wei).

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 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 saturation²¹ 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 sample²² 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".

The first interview ($n = 10$) lasted from 60 to 90 min ($\mu = 75$ min). The second interview ($n = 11$) lasted between 30 and 60 min ($\mu = 40$) in person ($n = 3$) or by phone ($n = 8$) per parent's preference. Field notes were taken during interviews to help authors put interview data in context during analysis. Parents' demographic information such as age, ethnicity, education, marital status, and family income was collected for general descriptive purposes.

Data analysis

We analyzed the interview data using directed content analysis,²⁴ which is one of the approaches of qualitative content analysis. With the directed content analysis approach, the initial coding themes are established based on an existing theory that guides the data analysis.²⁴

The guiding theory for this study was Swanson Caring Theory.^{1,4,5} Based on the theory, caring for others consists of the following processes: *knowing*, *being with*, *doing for*, *enabling*, and *maintaining belief*. These caring processes served as our initial coding themes to categorize parents' descriptions of their interactions with healthcare providers. To maintain humanistic characteristics of the narratives, we used pseudonyms instead of participants' numbers.

During the coding process, we remained mindful of observing narratives that were both captured and not captured by the theory. The analytic process included the following steps: a) reading transcripts several times thoroughly to get a sense of parents' overall experiences; b) identifying passages where parents described interactions with healthcare providers or hospital personnel; c) using the five caring processes of Swanson Caring Theory to categorize parents' descriptions of providers' actions; d) writing memos regarding reflections, insights, and questions about parents' descriptions of providers' actions; and e) coding passages into one of the caring processes based on the main intent that parents primarily tried to communicate.

Strategies to achieve rigor in the study

To generate resonant appraisals of parents' perceptions of healthcare providers' caring, we have followed Sandelowski's^{25,26} suggestions to maintain the rigor of our research. To ensure the truth value (credibility), we made sure that our findings were truthful to parents' descriptions and were faithful portrayals of parents' views. To warrant the applicability (fittingness), we targeted on parents of children with CHD undergoing their first heart surgery with the purpose of finding patterns of parents' outlooks on providers' caring actions during their specific context. To uphold consistency (auditability), our team members had maintained transparency of our research process and kept a clear audit trail from the beginning of the study, the design of the study, up till the presentation of our findings. Our team members used ATLAS.ti, version 7.5.6 for Windows²⁷ to code data and manage memos. For neutrality (confirmability), we made sure that our findings represented the data as a whole and were based on quotes across parents and that we used triangulation to ensure that our findings were consistent with all our data sources.

Results

Description of the sample

Twenty-one interviews were conducted with 13 parents from 10 families (10 mothers and 3 fathers). After the interview of the 13th parent, our team agreed that informational saturation²¹ had been

Table 1
Demographics of parents.

Parents (N = 13)	Mothers (n = 10)	Fathers (n = 3)	Families (N = 10)
Education			
Not high school graduate	1	1	
High school graduate		2	
Associate in science	7		
Bachelor of science	1		
Ethnicity			
African American	5		
Caucasian	4	2	
Hispanic	1	1	
Age			
<20	1		
20–29	4	2	
30–39	4	1	
40–49	1		
Family income			
< \$40,000			6
\$40,000–\$59,000			2
> \$60,000			2

reached; thus, we stopped further recruitment. Participants were parents of children with CHD, whose demographics were listed in Table 1. Their children's age, gender, type of CHD, and surgical procedures were displayed in Table 2.

Categorizing providers' actions into the caring processes

Knowing

Parents perceived *knowing* as providers' trying to understand their experiences and needs and how these might change over time as their child and family situations change. When first hearing their child's diagnosis of CHD, parents were devastated. They appreciated that providers tried to understand what they were going through physically and emotionally. They wanted providers to know that the way providers interacted with them could shape their reactions to their child's condition. A mother, Lyra, said, "At a local hospital where I delivered my son, I was informed about his diagnosis. When my pediatrician came in, her voice was very low. She sounded really sad, which made me feel [that] my son's condition was really bad." Another mother, Kendra, said, "I like Dr. [surgeon's name] to talk to me [because] she was very uplifting. She answered my questions before I had asked [her]. She made me feel [that] she knew what I was going through." Lyra clarified, "When it comes to talking to patients and families, nurses' and physicians' tone of voice and facial expressions can go a hundred million miles."

Parents appreciated a hospital environment in which healthcare providers cared about not only the child, but the whole family. Lani said, "When a child is hospitalized, the whole family is affected.

Table 2
Demographics of children.

Children (N = 10)	Boys (n = 9)	Girls (n = 1)
Age		
<1 y.o	7	
1–2 y.o	2	
5 y.o		1
Type of heart defects/Surgical procedures		
Atrial Septal Defect/ASD repair	1	
Ventricular Septal Defect/VSD repair	3	1
Atrial Ventricular Septal Defect/AVSD repair	1	
Tetralogy of Fallot/TET repair	3	
Pulmonary Stenosis/Pulmonary Valvotomy	1	

You've got to address the whole family's needs." Another mother, Aster, said, "When my son was here, they cared not only about my son, but also me. They made things easier for us, the food, the sleep, and the visiting hours, which made us feel understood and valued."

Being with

Parents perceived *being with* as providers' trying to accompany alongside them through their difficult times and be mindful about how their experiences affect them physically, emotionally, cognitively, and spiritually. Parents described four particularly vulnerable times for them, which were when parents received their child's diagnosis of CHD, handed their child over to the surgical staff in the pre-operative room, waited during their child's heart surgery, and visited their child for the first time after surgery. Parents appreciated the assurance from those healthcare providers who understood how they felt and would do whatever was necessary to connect with them and be mindful of their needs and experiences. Aster cried as she explained, "When my son was in surgery, I cried uncontrollably. I wanted someone to be with me, give me a little hand-holding, and tell me he's going to be okay." Aster was seeking physical, cognitive, emotional, and spiritual connections with her providers. Parents' narratives elucidated that they needed to be assured that their child's providers were mindful of the trust parents were giving them by handing their child over to them.

Parents respected those providers who were willing and ready to relate to them on a human to human level. Lani said, "When doctors told us about our son's diagnosis, our nurse stood right there with us. Her willingness to be there for us made me feel 'yeah I am not alone and I can get through this traumatic situation'". Lani's testimony showed the importance for providers to work together to provide them anticipatory guidance and be present with them physically and emotionally during their difficult times. It is vital that providers convey their understanding of parents' difficulties and have a willingness to endure the journey with them.

Doing for

Parents described *doing for* as providers' efforts to anticipate and undertake the things that parents would do for themselves if they were able to and/or knew how. After heart surgery, parents were generally sleep deprived, but were still reluctant to leave or rest for fear that their child might need them. Parents felt touched when providers acted on their behalf to assure them that their child was well cared for and to make parents feel comfortable to leave and rest. Ari said, "Nurses literally sat by my son for 24 h. They constantly asked me if I needed anything and encouraged me to go and rest. I was reluctant at first, but they made me feel comfortable and safe to leave." Lyra stated, "I was sleeping. My nurse came in and changed my baby's diaper. I could have done it, but she did it without waking me up, allowing us, the tired parents, to get rest during this challenging time."

When healthcare providers worked together as a team, parents considered their actions as caring. From parents' perspectives, nurses and physicians as well as other hospital personnel played a vital role in shaping their hospital experiences. When healthcare providers and other personnel worked together as a team, parents described their burdens shared and their stress loads lightened. One mother, Auden, clarified, "Everywhere we went, he [my son] had a team. That they all worked together taking care of him was what helped me the most." A father, Jerry, said, "When my son's oxygen level was low, nurses who weren't even his nurses came in to check on him." Kendra clarified: "Even if his nurse was in another room. If I said I needed anything, a pillow or anything, it was given to me right away. Everybody was attentive."

Although these actions previously described could be performed as routine professional actions (e.g., attending to an alarm),

parents appraised these actions as caring actions in the particular context. Parents knew there was a difference between an action that came from a place of caring about their experiences and an action that was done as a part of a job. Lani clarified that it is the culmination of many seemingly small actions that creates a culture and environment of caring and healing, "Everything you all [healthcare providers] do means a lot to us [family]. Nothing is too small to a family and a child who is sick in a hospital."

Enabling

Parents perceived *enabling* as providers' facilitation and encouragement for them to participate and to maintain their parental roles and decisional control even at difficult times. Parents referred to their child's heart surgery as a critical event for their family, an event that could change their family's fate. Parents were terrified for their child to go through heart surgery. Auden explained, "This could be the last time we saw him. I felt as if a chunk of my heart were taken away." Another mother, Tara, revealed, "He's my baby. If I were to let him go [to surgery], he wouldn't be mine anymore. I cannot hold him and comfort him [sobbing]."

Parents compared their child's heart surgery to a big mountain to climb. Parents indicated that they could not conquer the mountain without guidance and support from their providers. Parents signified that the time of handing their child over to the surgical staff was a critical moment when they experienced a loss in their parental role to act on behalf of their child's needs. As one father, Jerald, explained, "I am his parent. I don't want anything bad to happen to him. But knowing what he had to go through and [that] I cannot do anything about it is hard." More than half of the parents said that prayers helped them cope with their fears and anxieties of uncertainty before and during their child's heart surgery. Ari explained, "What kept me calm in the pre-operating area was praying." Parents also requested their family and friends on social media to pray for their child and family during the difficult times.

After surgery, when parents went to see their child in the PICU for the first time, they had a hard time adjusting to their child's appearance and the PICU's highly technical environment. Tara clarified, "I could not see my son. All [that] I saw were people, machines, and blood coming from the tubes in his chest." Kendra explained: "When I went to PICU, I saw my son had IVs in his neck, hand, and foot. Everything was bandaged up. I wanted to comfort him, but I am afraid [that] I might hurt him. That was really rough."

Parents' narratives conveyed that they experienced extreme fear and a sense of loss for their parental role while their child was in surgery and in the PICU. They ached to comfort their child, but were reluctant because they were scared to be in the way or to inadvertently harm their child. Parents needed providers to explain the expected outcomes of surgery and encourage and guide them to perform parenting tasks in the context of the highly technical environment. Della explained, "I was afraid to touch my daughter because of the wires and tubes. A nurse told me [that] I could give her a bath if I wanted to. She guided me through it. It made me feel great."

Maintaining belief

Parents described this as a belief that providers conveyed to parents that their family could get through their child's hospitalization, surgery, and post-operative care and face a future with positive meaning for their family. When parents were first informed about their child's diagnosis, they were overwhelmed by uncertainties. Kady explained, "I was numb at the time and did not know what to think." Jerald further clarified their initial shock of diagnosis and the need for surgery by explaining that "Before my son's diagnosis, I did not know this place [children's cardiac care unit] had existed. I thought when people had babies, they would be

well and go home.” Because parents had no previous knowledge that prepared them for this outcome, they struggled to know how to overcome the big mountain that was now in front of them.

Parents explained that they needed to be encouraged to use their resiliency and strengths to get through their situation. They wanted providers to offer step-by-step anticipatory guidance and emotional support so that they could make informed decisions, stay involved in their child’s care, and feel reasonably optimistic about their child’s outcomes and their families’ well-being. Tina elucidated the importance of believing in the family’s ability to overcome the mountain by explaining how her providers helped her, “We knew about our son’s heart defect during pregnancy. We were very upset initially till we saw the cardiologist. Everyone there was positive about the whole thing. Because of them, we had a great pregnancy.” Her husband, Jerry, conveyed how the notion of having his son undergoing heart surgery to correct his heart defects helped him think about the positive possibilities of their family’s future, “The doctors took their time to explain my son’s conditions and treatment plans. I was actually looking forward to the heart surgery so that he [my son] could [eventually] run around playing baseball.”

Even though healthcare providers had to explain negative risks of their child’s heart surgery, parents appreciated that providers used uplifting and positive attitudes when framing information about their child’s condition and treatment. When placed in the middle of the caring processes, *knowing, being with, doing for, enabling, and maintaining belief*, parents felt understood, valued, hopeful, and cared for.

Discussion

Parents’ testimonies regarding their experiences of receiving care are important quality of care indicators. In this article, we examined parents’ perceptions of care when their child with CHD underwent heart surgery. According to parents, caring actions are those through which healthcare providers continuously attempt to connect with them, understand their values and needs, and work together as a team to care for their child and their family as a whole. The five caring processes of Swanson Caring Theory have captured parents’ notions of caring during their child’s diagnosis and surgery. From parents’ narratives, we have found that healthcare providers play an imperative role in helping parents understand and adjust to their child’s ongoing medical conditions, the effective ways of doing which are to include them in their child’s treatment and validated their roles as parents by incorporating them in their child’s daily hospital care.

When children are diagnosed with CHD and undergo heart surgery, parents endure four critical moments: a) when they are first informed about their child’s heart defect(s) and need for cardiac surgery; b) when they relinquish their child’s care to the surgical team; c) while they wait for their child’s surgery to be over; and d) when parents arrive in the PICU and see their child for the first time after surgery. Similar to other studies’ findings,^{13,28–30} our findings indicated that during the critical times, parents experienced intensely heightened uncertainties due to an unexpected diagnosis, grief for the potential loss of their child, and despair of feeling helpless in protecting their child. We found, however, that although parents were vulnerable during these times, providers could make a difference. Healthcare providers could use anticipatory guidance^{31,32} to build upon parents’ positive coping mechanisms and proactively coach them what to expect at the moments and into the future. Parents appreciated providers’ guidance and non-judgmental understanding, which enabled their coping and provided them physical and emotional support and comfort.

The findings of this study provide evidence that the promotion of healing involves a combination of the science of biomedicine and the

art of human caring.² When children undergo cardiac surgery, their parents suffer emotionally. Healthcare providers need to not only use technology to fix children’s physical hearts, but also apply caring to remedy parents’ emotions. Based on parents’ experiences¹³ and perceptions of caring, parents indicated that heart surgery was a technical procedure that had fixed their child’s heart; but what had helped them go through the procedure emotionally were providers’ caring actions that were conveyed through providers’ attempts to ask, listen, understand, connect, walk alongside them, involve them in decision making and empower them to care and comfort their child. During their child’s hospitalization, it is the culmination of the science of biomedicine and the art of providers’ caring that empowers parents to face the challenges of parenting a child in the highly technical hospital environment and have the anticipation of a bright future for their child and family. In studies with other patient populations, when caring actions were enacted, couples who miscarried reported less symptoms of depression,³³ a lung cancer patient who had lost hope for the future regained courage to live,³⁴ patients in preoperative settings reported decreased anxiety and stress,³⁵ and patients with hypertension showed better results in blood pressure control and higher quality of life.³⁶ These findings indicate that patients observe and respond positively to healthcare providers’ attitudes and actions during their healthcare encounters and provide a compelling case for the importance of caring as an integral component in healthcare practice.

This study has showed that caring for patients and parents is a holistic process that addresses parents’ physical, informational, spiritual, and psychological health. Similar to the findings of Lawoko,³⁷ we found that parents wanted to be supported to enact their parental role in hospitals and be attended to holistically across the process of their child’s diagnosis and treatment. Other studies have revealed substantial needs to use a holistic care approach in healthcare³⁸ to promote patients’ well-being.^{2,5,39} During hospitalizations, when parents show spiritual needs such as prayer requests, it is a key point in time to incorporate hospital chaplains. Parents in this study demonstrated the importance of family-centered care,⁴⁰ wherein healthcare providers focused on both the child who was sick and the parents who accompanied that child. Parents voiced that when a child was sick in hospitals, nothing that healthcare providers could do for the child and his/her parents would be too small.

Our findings have revealed that effective communication is vital in connecting with parents. Providers’ thoughtful and encouraging communications can help parents be confident in performing their parental roles in hospitals and optimistic about the future of their child and their family. Alike other researchers’ findings,^{41,42} this study shows that healthcare providers’ encouraging communications support parents to feel prepared and confident to participate in their child’s care and decision-making processes. Parents discern meaning by paying attention to the entirety of providers’ communication, including their verbal and non-verbal actions. They gauge providers’ word emphasis, tones of speaking, and body movements, as well as the parts that they leave out. Comparable to other researchers’ findings,^{17,43,44} we have found that verbal and non-verbal communications between parents and providers can facilitate or hinder parents’ willingness to share their experiences and concerns.

Limitations and future research

With a qualitative approach, small sample size, and convenience sample, we caution against generalizing these findings to all parents’ experiences. Nonetheless, we were able to query a group of socio-economically diverse parents whose children were diagnosed with various kinds of CHD. We did not detect differences in parents’

perceptions of caring related to parents' diverse background, the gender of their child, or the nature or procedures of their child's CHD.

Based on parents' perceptions of providers' caring actions, future studies may consider developing clinical practice models that promote parents' involvement in their child's care during heart surgery. Studies are necessary to identify strategies to enable parents to participate in their child's care at the time when their child needs their attention and comfort the most.

Conclusions and clinical implications

This study has provided insights into parents' notions of caring when their child with CHD undergoes heart surgery. Healthcare providers' actions and interactions with patients, parents, and one another can shape parents' perceived culture of caring in a hospital system. Healthcare is facing major changes in the United States, where patients' experiences are quality indicators that influence healthcare organizations' economic well-being such as reimbursement rates. When human caring is the underpinning in healthcare, parents' experiences are promoted and patients' quality of care is enhanced, whereby organizations' reputation and economic wellbeing are improved; thereby, all entities who are involved in healthcare are beneficiaries.

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