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Care of Families of Children With Cardiac Disorders

## Parents' experiences of having a child undergoing congenital heart surgery: An emotional rollercoaster from shocking to blessing

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## ABSTRACT

**Objectives:** To describe parents' experiences when their child with congenital heart disease (CHD) underwent heart surgery.**Background:** About 40,000 children are born with CHD in the United States each year. Very few studies have explored parents' experiences when their child was diagnosed with CHD and underwent heart surgery.**Methods:** Descriptive phenomenology informed this study that consisted of two interviews with 13 parents.**Results:** Parents experienced a "rollercoaster" of emotions. Critical times were when parents received their child's diagnosis, handed their child over to the surgical team, and visited their child in the pediatric intensive care unit after surgery. Related stressors were the uncertainty of outcomes after surgery, the loss of parental control, the physical appearance of their child, and the fear of the technological atmosphere in the intensive care unit.**Conclusions:** The ups and downs of parents' emotions reflected their child's changing condition and parents' adjustment to the condition.

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## Introduction

Congenital heart disease (CHD) is the most prevalent birth defect in the United States. Each year, 40,000 children are born with CHD and about 10,000 of these children need heart surgery.<sup>1</sup>

Congenital heart disease is among the birth defects that lead to the longest hospital stays and highest mortality rate.<sup>2</sup> Children with CHD require frequent hospitalizations.<sup>3</sup>

The treatment for CHD has been improving. In 2000 and 2002, the National Heart, Lung, and Blood Institute sent out two major initiatives to promote treatment interventions and clinical research for children with heart disease. Since 2000, research on families of children with CHD has mainly focused on the impact of a child's CHD on parents' psychological health, their family life, parenting experiences, and the relationships between parents' psychological symptoms and child's behaviors.<sup>4</sup>

Parents' psychological health was a main research focus in the past 15 years.<sup>4</sup> Using parents' self-report surveys, majority of the researchers found that parents of children with CHD reported higher levels of psychological symptoms, such as stress, anxiety, or depression, than parents of children without CHD<sup>5–9</sup>; yet a few

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researchers found that parents of children with CHD had a lower level of psychological symptoms than normative samples.<sup>10,11</sup>

As discussed in a review on families of children with CHD,<sup>4</sup> qualitative narrative techniques may facilitate self-report surveys to help us understand parents of children with CHD. When using both parents' self-report surveys and interviews to study parents' psychological symptoms, researchers understood more about parents' stress symptoms through interviews than the self-report questionnaires.<sup>12</sup> Jordan et al<sup>13</sup> also found that mothers reported more negative influences of their infant's heart surgery on their bonding during interviews than through self-report surveys. Vrijmoet-Wiersma et al<sup>14</sup> discussed that to understand the experiences of parents of children with CHD, self-report questionnaires might not be sufficient.

In the past 15 years, fewer than 30 studies were qualitative studies worldwide, in which researchers used interview techniques to understand parents' experiences when they had a child with CHD.<sup>4</sup> About one third of these studies examined a number of parents in Canada whose children were born with Hypoplastic Left Heart Syndrome. This syndrome is a non-curative type of CHD, affecting about 960 children in the United States each year, with an incidence rate of 1 in 4344 live births.<sup>15</sup> Researchers found that parents of children with Hypoplastic Left Heart Syndrome were highly vigilant about their child's health conditions; had to face and overcome many uncertainties in decision making and outcomes; tried to protect their child's survival; and strived to provide their child as a normal life as possible.<sup>16–19</sup>

Among the qualitative studies of families of children with CHD,<sup>4</sup> fewer than 10 were conducted in the United States since 2000. These studies mainly examined the meaning of costs when parents had a child with CHD,<sup>20</sup> the relationships between mothers and teenage daughters who were diagnosed with heart disease in their childhood,<sup>21</sup> the experiences of five couples who had a child with CHD that did or did not require surgical treatment,<sup>22</sup> and parents' motivations of parenting their infant with CHD during his/her first year.<sup>23</sup> The diverse focus of the research makes it hard to understand patterns that could lead to interventions to help parents.

Very little research has explored the patterns of parents' experiences as their child went through the course of diagnosis of CHD and heart surgery. Understanding parents' experiences during the course of their child's diagnosis and heart surgery could be a substantial contribution to the care of families of children with CHD. Therefore, this study described parents' experiences when their child with CHD underwent heart surgery.

## Methods

This study was approved by the Institutional Review Board at the university and the Nursing Research Council at the study hospital.

### Design

This was a descriptive phenomenological study. Descriptive phenomenology is intended to describe individuals' experiences of a phenomenon without presumptions.<sup>24</sup>

### Sample and setting

This study was carried out in a children's hospital located on the east coast of the United States. Recruitment took place on a pediatric cardiac unit between July and December 2014. Because it was not clear whether the severity of CHD and parents' socioeconomic background affected parents' experience,<sup>4</sup> we used a convenience sampling method. We invited parents to participate if they had a

child hospitalized for his/her first open heart surgery, were at least 18 years old of any race, and spoke and read English. No parents declined when invited. One parent from each family was required to participate; but both parents were welcome. If both parents were in the study, they were interviewed individually.

The precise sample size needed for phenomenological studies is hard to decide beforehand. Recommendations for sample size are between 5 and 25 participants.<sup>25</sup> We used informational redundancy as a guide in deciding the adequacy of the sample size.<sup>26</sup> In this study, after the seventh parent, we could see patterns of themes. After the tenth parent, we saw information redundancy. We stopped recruiting after the thirteenth parent was interviewed and the data was analyzed when saturation of themes was reached.

### Data collection

Two forms of data were collected, a demographic survey and in-depth interviews. Parents' written informed consent was obtained before their first interview. Pseudonyms were assigned to each participant to protect their privacy and preserve a humanistic characteristic. Two interviews per parent were conducted if parents were available and willing. The first interview was about a week after the child's heart surgery, and the second interview occurred 4–6 weeks after the first interview. Parents completed the demographic form before their first interviews. The first interview was conducted in-person on the cardiac unit. The second interview was done in person or by phone depending on parents' choice. One parent per family was required to participate; both parents were welcome. If both parents participated, they were interviewed separately. The interviews lasted about an hour and were transcribed verbatim.

The first interview was designed to inquire about parents' experiences upon receiving their child's diagnosis, going through heart surgery, seeing their child after surgery, and being transferred from an ICU to a regular cardiac floor. The intention for the second interview was to allow parents to reflect on the entire experience from diagnosis to discharge. Interview questions were developed based on the purpose of the study. Selected interview questions and probing questions are listed in Table 1.

### Data analysis

Combining the data analysis methods of Colaizzi,<sup>27</sup> Giorgi,<sup>28</sup> Swanson-Kauffman and Schonwald,<sup>29</sup> Wojnar and Swanson,<sup>24</sup> and Wojnar, Swanson, and Adolffson,<sup>30</sup> the authors used a team effort to conduct the data analysis. The process included (a) assembling a coding team; (b) starting analysis along with data collection; (c) reading transcript data thoroughly, which could take multiple times to gain a general sense of participants' overall experiences; (d) bracketing when looking for patterns; (e) writing memos while reading; (f) extracting significant statements about parents' experiences; (g) assigning meanings to the extracted statements; (h) finding commonalities across data; (i) intuiting on the data and reflecting meanings; (j) categorizing the meanings into groups of themes shared by participants; (k) describing parents' verbal descriptions in a written form; (l) validating the data via parents' member checks; and (m) incorporating parents' suggestions into a final report. To aid the analytic process, authors used ATLAS.ti, version 7.5.6 for windows.<sup>31</sup> The authors used the software to link codes to parents' narratives, track codes among coders, and maintain a clear audit trail during the analytic process.

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