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Experience of fathers of neonates with congenital heart disease in South Korea

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ABSTRACT

Background: Although the 1st month is critical for establishing fatherhood, rare studies have focused on this topic.

Objective: To understand experiences of fathers of neonates with congenital heart disease.

Methods: Descriptive phenomenology study.

Results: The fathers were initially unaware of the seriousness of their neonates' condition. After they learned about it, they felt despair. They experienced guilt regarding their neonates' diagnosis and tried to take full responsibility for the situation to save their family from crisis. Furthermore, they were anxious because they could not do anything except wait for surgery. Their despair turned into gratitude post-operatively, and they developed positive views. Despite intending to be caring and affectionate, they returned to their socially assigned role as providers and passed on the caregiver role to the mothers.

Conclusion: Healthcare providers should assess anxiety levels and support fathers of neonates with congenital heart disease to help them develop their paternal role.

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Introduction

Congenital heart disease in neonates leads to hypoxic organ damage¹ and requires immediate surgery after birth.² Parents of neonates diagnosed with congenital heart disease have demonstrated high levels of stress because of uncertainties of the disease, unexpected surgery, and possible negative health consequences that might influence the neonates future^{3,4} as well as instability, hurt, and feelings of guilt stemming from a lack of knowledge of the cause of the disease.⁵ In such situations, fathers experience sadness, feelings of loss, and fear that their neonates may die, which all build into a crisis.^{3,6} This event could alter neonate fathers' transitions to fatherhood because the 1st month with the baby is a very important time, during which the father begins to form an identity as a parent. From childbirth, the parent experiences expectations and insecurity regarding the newly bestowed parental role⁷ as well as psychological hardships resulting from the diagnosis.⁸ During the

process of forming an identity as a father, a man may have a difficult time adapting to changes in daily life and added responsibilities as a parent.^{9,10}

Fathers provide economic and emotional support to the family during the progress of their children's disease¹¹ and take on the role of reducing family stress caused by the disease.¹² Fathers also provide a positive influence on the development of the hospitalized neonate and aid in the neonate's emotional stability,^{2,13} all of which constitute very important roles in deciding the direction of care in emergency situations.¹⁴ In addition to their traditional role as the economic and emotional support of the family,^{9,15} Korean fathers now especially take on new supportive and childcare roles in the family, given the new societal trends of a heightened desire for women's social participation and feminism in Korea.¹⁰

Although the manner in which a father plays the leading role is important for family members to endure the crisis, majority of extant studies have focused on the experience of mothers,^{1,16,17} and experiences of fathers in taking on their father role is not well explored. Therefore, in this study, we aimed to understand experiences of fathers during the progression of their neonate's congenital heart disease and to strategize supportive intervention strategies that healthcare professionals could realistically use in clinical settings, by documenting experiences of fathers with neonates diagnosed with congenital heart disease.

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Methods

Design

We used a descriptive phenomenology approach to explore the experience of fathers of neonates with congenital heart disease. Phenomenological research is a methodology that documents the experiential significance of individuals regarding a concept or a phenomenon. This approach is appropriate to document and understand the significance of the experiences of participants in real-life situations.¹⁸

Participants and setting

Participants in this study were fathers of neonates with congenital heart disease. We recruited participants from a tertiary hospital located in Seoul, South Korea. All neonates with congenital heart disease were the first child in their families and received surgery within a month of birth. Postoperatively, the neonates were transferred to general wards, after spending some time in the neonatal intensive care unit. Recruitment took place after transfer to the general wards. Six fathers of neonates with congenital heart disease participated in the study.

Data collection

Data collection took place between May and December 2015. We conducted one-on-one interviews with participants until reaching saturation, such that no new experiences emerged. To secure the ethical principles of the participants, we explained the purpose and method of the study, recorded the interviews, and guaranteed confidentiality. We also explained that the interview content would be used only for the purpose of research and that participants were free to withdraw from the study at any time with no consequences.

We conducted the one-on-one interviews with each participant for 60–90 min. We recorded all interviews with the participants' agreement. Interviews were transcribed verbatim. Interview questions focused on experiences of a father of a neonate with congenital heart disease, the experience of participating in the treatment process of neonates, and the perceived role of fathers. The main interview question was "Tell me about your experience of being the father of a neonate with congenital heart disease."

Data analysis

To identify the nature of the experience, this study used the analysis method suggested by Colaizzi.^{18,19} The analysis process consisted of (a) reading the transcripts of the study as a whole and understanding the meaning of the experience, (b) selecting meaningful sentences or words to extract significant responses, (c) excluding duplicate responses and forming clear meanings and then presenting it again in the words of the researcher, (d) forming meanings based on the content extracted from responses, (e) providing overall accounts of topics based on analyzed data, (f) exhaustively describing the core nature of the phenomenon experienced by participants based on analyzed data, and (g) acquiring validation of the research results by communicating the results with the participants. The reliability of this study was evaluated based on the four criteria for evaluating qualitative studies, as suggested by Lincoln and Guba,¹⁹ namely credibility, dependability, transferability, and confirmability.

Results

The demographic characteristics of the participants are described in Table 1. The participants' ages ranged between 30 and 44 years, and all were working full time. The neonates of the participants were diagnosed with the following diseases: ventricular septal defect ($n = 2$), ventricular septal defect with coarctation of the aorta ($n = 2$), total anomalous pulmonary vein return ($n = 1$), and pulmonary atresia with intact ventricular septum ($n = 1$). Of the six participants, five were unaware of their neonates' diagnosis before birth: five neonates were diagnosed with congenital heart disease between 1 and 5 days after birth. Data analysis revealed eight main themes describing experiences of the father of a neonate with congenital heart disease (see Table 2).

Initially unaware of the seriousness of the disease

Of the six participants, five did not receive their newborn's diagnosis until after birth. Although the participants learned about the health of their neonate, they assumed the condition was trivial. They thought that the neonate would be healthy because no problems arose during the prenatal period, and the participants themselves had been healthy. Even after receiving the diagnosis, they failed to understand the seriousness and believed that the disease would be cured naturally. Some of them believed that the condition might be one that others also develop. Moreover, the fathers denied results as not being pertinent to them and failed to emotionally embrace the diagnosis. Participant 1 said,

"I didn't think much of it because from the perspective of my health, I was normal [healthy], and I didn't have too many health problems. I thought that because we [wife and I] were healthy, the neonate would also be healthy."

Participant 4 said, "These holes in hearts seemed to be pretty common, I thought ... I thought it was something like that ... nothing too serious."

Falling into despair after learning about the severity of the disease

After being notified regarding the need of a transfer to a bigger hospital or of a heart surgery for the neonate, participants became

Table 1
Demographics (on page 5).

Demographic profile	N = 6
Age	
30–34	1
35–39	4
40–44	1
Occupation	
Car mechanic	1
General contractor	1
Social worker	1
Businessman	3
Family income	
Below \$30,000	2
\$30,000–\$40,000	2
\$40,000–\$50,000	1
\$50,000–\$60,000	1
Types of heart defect of neonates	
Ventricular septal defect	2
Ventricular septal defect with coarctation of aorta	2
Total anomalous pulmonary vein return	1
Pulmonary atresia with intact ventricular septum	1
Time of neonate's diagnosis	
Prenatal	1
Postnatal	5

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