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Research Article

# The Lived Experience of First-time Mothers with Congenital Heart Disease

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SUMMARY

*Purpose:* Nowadays most children with congenital heart disease (CHD) are expected to survive to adulthood. The healthcare focus needs to pay close attention to the important developmental tasks during their growth process. The women with CHD face some challenges in their critically developmental stages during pregnancy, delivery, and even motherhood. The lived experience of being a mother needs to be further concerned. This study aimed to explore the lived experience of first-time mothers with CHD.

*Methods:* Descriptive phenomenological design was adopted. Semi-structured interviews were conducted from April to August 2018 with 11 primiparous women with CHD, who were recruited from the pediatric and adult cardiology outpatient departments at a medical center and who had a child aged between 6 months and 3 years. Giorgi's phenomenological analysis method was employed.

*Results:* Six main themes arose from the analysis: (1) recognizing pregnancy risks, (2) performing self-care for health, (3) building self-worth from my baby, (4) adapting to postpartum life and adjusting priorities, (5) enjoying being a first-time mother, and (6) the factors contributing to success in high-risk childbirth.

*Conclusions:* The experiences that occurred prior to and after labor that were identified in this study can assist women with CHD to more capably prepare for and understand the process of becoming a mother, including recognition of the importance of a prepregnancy evaluation. The findings of this study can help women with CHD to better understand the path to becoming a mother and prepare themselves for the challenges that lie ahead.



## Introduction

Congenital heart disease (CHD) is the most common congenital circulatory malformation in newborns. Depending on its severity, it affects normal life functions. The prevalence of CHD in screened children by year from 2002 to 2018 ranged from 5.1/1,000 to 7.3/1,000 in Taiwan [1]. However, due to the development of medical technology, more than 90.0% of patients can survive into adulthood, but long-term follow-up is required [2]. The needs of these patients with respect to the physical, mental, social, and spiritual aspects of life are a worthy object of study. One of the major life events that women with CHD are likely to experience is becoming pregnant and being a mother.

Men with CHD are concerned about their performance during sexual intercourse, whereas women with CHD are concerned about problems related to pregnancy and childbearing [3,4]. Upon reaching childbearing age, women with CHD must prepare for pregnancy if they desire it. Women with differing heart disease severity face different levels of pregnancy risk. Studies examining the hemodynamic changes in women with CHD during their pregnancy have indicated that the cardiac output of these women is 30–50.0% higher than that of themselves when they are not pregnant, and this higher cardiac output can lead to elevated risk of cardiovascular diseases [5]. Additionally, compared with their

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counterparts without CHD, women with CHD are more likely to experience pregnancy complications and have their children inheriting CHD [6]. When the mother has chronic diseases or delayed childbirth, the child's risk of CHD will also increase [7]. In summary, CHD is a medical condition that can threaten the health of both mother and baby. According to the aforementioned difficulties faced by women with CHD during their pregnancy and during labor, their physical discomfort and more importantly their psychological stress during pregnancy should both not be overlooked [4]. However, the conviction resulting from the wish to become a mother can be a strong force, and this force can sustain the mother-to-be in their long battle against various preconception and postconception challenges not faced by women without CHD [8]. In an effort to pursue higher quality of life and prepare for the hazardous events that may occur during pregnancy, women with CHD pay great attention to their health during pregnancy [9]. Nevertheless, women with CHD remain uncertain whether they will be able to maintain their health with regard to the high risks they face.

The maternal role theories of Rubin [10] and Mercer [11] state that being a mother is an important step in women's personal development. After the child is born, the woman inhabits the role of mother. The mother–infant relationship and attachment are typically established between the primary caretaker and infant within their first year of interaction. The unconscious behaviors of a mother originate from her exploration of the attachment relationship between herself and her child. A healthy attachment relationship involves a reciprocal process between a mother and her child, and the mother–child attachment relationship affects the mother's emotions, the child's temperament, and the child's future development [12]. Nevertheless, chronic diseases can threaten the functioning of a woman in her socialized role. When a mother cannot take care of her child in the way she wants, she may experience negative emotions such as anxiety, depression, or guilt. Many women diagnosed with diseases wish to be become a good mother [9]. However, the physical and psychological burdens caused by their diseases may lessen their child-rearing ability. Women still expect to be able to raise children. Some women with CHD even think that being a mother is more important than properly caring for their condition. Being a mother can make women with CHD feel that they belong in society [8].

The label “disease” sometimes causes people to overemphasize the pathological characteristics of an individual and to ignore that individual's unique personal traits and advantages. Understanding and analyzing the processes that women with CHD go through to become a mother is crucial and necessary. Quality of life, health promotion, lifestyle, and pregnancy risk are some of the topics often discussed in relation to women with CHD in nursing studies. However, studies examining the lived experience of first-time mothers with CHD are relatively rare [4,8,9]. We conducted qualitative interviews to examine the upbringing of women with CHD, their life experiences after becoming a mother for the first time, their thoughts and feelings, and how these perceptions affected their execution of the maternal role. We hoped to explore the essence of lived experience of first-time mothers with CHD.

## Methods

### Design

This study employed a descriptive phenomenological design applying Giorgi's (2009) phenomenological method with in-depth interviews to understand the lived experience of women with CHD on their first-time motherhood.

### Participants and setting

Purposive sampling was used to select participants. The participants were recruited from the pediatric and adult CHD specialist outpatient clinic at a medical center in Northern Taiwan. Mercer's [11,13] maternal role theory states that the mother's experience of the childbirth process will affect her ability to perform the maternal role at 6 months postpartum, and parent–child attachment will begin to shift when the child is approximately 3 years old. The inclusion criteria were as follows: (1) primiparous women with CHD and a child aged between 6 months and 3 years; (2) women who lived with their biological child(ren) and were one of the primary caretakers of their child(ren); (3) women who were classified as having class II, III, or IV cardiovascular diseases according to the classification principles stated in the mWHO Classification of Maternal Cardiovascular Risk; (4) women with CHD not caused by chromosomal and genetic abnormalities (e.g., Marfan syndrome and Down syndrome) and with no other chronic disease or comorbidity; (5) women who could communicate in Taiwanese Mandarin could understand the theme of the interview.

The interview questions were developed based on the combination of literature review and the practical experiences of the researcher (the first author), and the suggestions provided by qualitative experts (the third, fourth and fifth authors) (Table 1). Before the study was begun, a pilot study with one participant interviewed was conducted to confirm the appropriateness and feasibility of the original interview guidelines met the aims of the study.

The formal data collection period with the original interview guidelines lasted from April to August 2018. The interviews with 11 women with CHD (coded A–K) provided detailed information on the individual's experience, views, and feelings of the first-time mothers with CHD. Characteristics of the study participants are shown in Table 2. The CHD conditions of the participants included both acyanotic and cyanotic heart diseases. Regarding their Modified World Health Organization (mWHO) severity, the majority of the participants (7/11, 63.6%) had class II cardiovascular diseases, with the others having class III (2/11, 18.2%), including diagnoses of transposition of the great arteries and total cavopulmonary connection or class IV (2/11, 18.2%) cardiovascular diseases, including diagnoses of atrial septal defect and tetralogy of Fallot. The participants were aged between 22 and 46 years, with an average age of 34.5 years. Among the participants, 81.8% was planned pregnancy and 72.7% was natural insemination. The participants had a total of 13 children, and two of the participants had twins. Regarding the demographic characteristics of their children, six (46.2%) of the children were male. The children weighed 1,176–2,954 g at birth, and their average age upon recruitment of their mother into the study was approximately 22.7 months.

### Data collection

Before commencing data collection, the researcher (the first author) briefed women who met the inclusion criteria about the content, purposes, and procedures of the current study in person. After obtaining the women's informed consent, the researchers then negotiated with each participant to schedule a suitable time and place for a one-to-one interview. Each participant was to be interviewed once. At the beginning of each interview, the researcher engaged in nonstructured conversation with the participant, so that the participant could relax before the main part of the interview started. Each interview lasted 1–2 hours, and the interviews were conducted in the participants' home or the café nearby their home. The interviews were recorded using a voice recorder. Nonverbal behaviors during the interviews—such as participants' tone of voice, expressions, and movements—were

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**Table 1** *Interview Questions.*

| |
|---|
| 1. How did you feel when you discovered you were going to become a mother? What is the significance of becoming a mother to you? |
| 2. This was the first time you became a mother. How did your actual feelings on becoming a mother differ from your expected feelings? |
| 3. This is your first child. What feelings did the child give you? How did your life change after you become a mother? |
| 4. The journey to becoming a mother is not an easy one. Can you share your experience of proactively seeking medical care and the types of medical resources that you accessed? Do you have any suggestions for women with CHD who are planning to have children? |
| 5. Hospitals currently provide some relevant medical resources to aid women with CHD to fulfill their maternal role. What is your opinion of this? Do you have any suggestions? |

CHD: congenital heart disease.

observed and recorded. To add to the comprehensiveness of the interview data, the researcher also recorded the interactions that occurred during the interview sessions and their own reflections on the interviews. The voice-recording file of each interview was transcribed into text within 24 hours of the interview for data processing and analysis. The research groups (all authors) then sorted, coded, and categorized the collected data of individual participants separately. Data collection and analysis were repeated until the point of data saturation, and participant recruitment was halted when no additional themes could be generated from the data analysis and when there was overlap of themes.

### *Data analysis*

The researchers used contrast, induction, and comparison methods to gradually develop the conceptions and themes of the interview content. For the data analysis, the five-step empirical phenomenological analysis method proposed by Giorgi [14] was employed. The analysis steps are as follows: (1) Phenological data were collected, and all transcripts were read to gain a global sense of the data. (2) The meaningful analysis units were identified. Then, by using trained sensitivity and an open attitude, a series of meaning units expressed in the words of the participants was identified. (3) The descriptive raw data were transformed into meaning units through the process of reflection and imaginative variation by using technical language in the field; these meaning units were then used as the basis for interpretation of the research question. (4) The themes were abstracted into key meanings; the basic features of each phenomenon were confirmed. (5) The specific structured descriptions of each participant were combined. In the general description of situated structure, the key meanings were compiled to form structured descriptions. The core concepts were captured by using phenomenological reduction and developed into the research results [14,15]. The process of data analysis from meaning units to theme is illustrated by an exemplar in Table 3.

### *Ethical considerations*

Ethical approval for the study was obtained from the institutional review board of the medical center (Approval No. 201712164RINC). The ethical principles were met through oral and written information about the study to the participants. Potential participants were called by the first author to query their interest in participating in the study. Participants were informed that the study was voluntary, and they could refuse participation in the study or withdraw at any time without affecting their treatment. Written consent was obtained. In the transcribed material and reports, codes were allocated to each participant and identifying information was removed.

### *Rigor*

To ensure the validity and reliability of the study, the researchers conducted the study in accordance with the research guidelines for qualitative studies proposed by Lincoln and Guba [16]. The phenomenological qualitative research method was used to collect data. The research questions were designed by an expert panel comprising a cardiologist, experts on CHD in children and adults, and experts on child developmental psychology. Interviews were conducted to investigate the first-time motherhood experiences of women with CHD, after which the voice-recording files were transcribed into text. The interview processes were properly recorded, and the records were ensured to reflect the actual interviews. Purposive sampling method was employed in the current study to ascertain the scope of participant selection. Understanding was obtained through listening; this understanding was used to identify problems; and assistance was provided accordingly. The following interview content was especially crucial: (1) the experiences of the participants regarding how they solved shared problems, and (2) the participants' expression of their needs and perceived processes. The results of the current study are applicable to the female population with CHD. The written records were cross-checked against the original records and revised accordingly. When conducting the research, we recorded our reflections in a daily diary. The purpose of this was to help us avoid bias by clarifying self-awareness and emphasizing the essences of phenomena. After objective analysis of the data, the results were cross-checked against the content of this reflection diary, ensuring the consistency and dependability of the data analysis.

## Results

In the text analysis process, the researchers reduced the meaning phrases of women with CHD to a coherent text. The researchers then transformed the 251 meaning units into technical languages, after which the content was coded and classified into 33 categories. Subsequently, the researchers integrated the categories into 18 subthemes of the current study. Finally, the subthemes were abstracted into six core concepts—the themes of the study (Table 4).

### *Theme 1: Recognizing pregnancy risks*

When women with CHD who participated in this study did not routinely seek relevant medical treatment, they did not have clear understanding of their own health status. Patients' poor understanding of their CHD also resulted in discrepancy between patient-perceived severity and professionally evaluated severity. Additionally, fear of pregnancy or unplanned pregnancies was observed among the women with CHD because of a lack of contraceptive and childbearing knowledge (D-26 in Table 4).

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**Table 2** *Demographic and Clinical Characteristics of the Study Participants (N = 11).*

| Characteristics | N / Mean (SD, min-max) |
|---|---|
| Age (years) | 34.2 (6.7, 22-46) |
| Education | |
| Master | 4 |
| College | 4 |
| Undergraduate | 2 |
| Vocational | 1 |
| Pregnancy intention | |
| Planned | 9 |
| Unplanned | 2 |
| Types of insemination | |
| Natural | 8 |
| Artificial | 3 |
| Numbers of children born | |
| Singleton | 9 |
| Twins | 2 |
| Diagnosis | |
| ASD | 2 |
| VSD | 2 |
| TOF | 2 |
| TGA | 1 |
| SV | 1 |
| DORV | 1 |
| COA | 1 |
| PDA | 1 |
| mWHO class | |
| II | 7 |
| III | 2 |
| IV | 2 |

ASD: atrial septal defect; VSD: ventricular septal defect; TOF: tetralogy of fallot; TGA: transposition of the great arteries; SV: single ventricle; DORV: double outlet right ventricle; COA: coarctation of aorta; PDA: patent ductus arteriosus; mWHO class: modified World Health Organization Classification of Maternal Cardiovascular Risk.

Once the participants had confirmed their pregnancy, they began to worry about the risk to their health and their child's health. The participants were scared that their CHD would hamper the development of their child. Because of uncertainties surrounding their own health and that of their child, they often experienced entangled thoughts, feelings of contradiction, and emotional conflict during their pregnancy. Most of the participants were concerned that their child would inherit their CHD; the next most common reflections were concerns about other uncertain risk factors and description of feelings of discomfort. In their reports, the women expressed negative emotions including worry and nervousness. If they could, most of the women with CHD acquired more detailed or additional and self-funded medical examinations; they only felt at ease if the examination results revealed that their child was healthy (I-12 in Table 4).

*Theme 2: Performing self-care for health*

When the participants were preparing themselves to be mothers, they began to pay more attention to their CHD-related health problems and better take care of themselves. They proactively visited hospital to seek help from physicians with the hope that they could obtain information relevant to pregnancy before conception. Additionally, they arranged for a preconception evaluation and other relevant medical examinations as well as discussing with physicians the possible symptoms and risks that could emerge during pregnancy. During pregnancy, they often worried about their future health and that of the unborn baby. They proactively sought to acquire knowledge and took precautions beneficial to the baby and themselves; they obtained disease information, took precautions for the pregnancy and labor, and acquired child-rearing knowledge. They aimed to optimize their body condition and eliminate risk factors with the aim of ensuring the safe and healthy delivery of their baby. In pursuit of these goals, they visited Chinese medicine clinics, sought advice from physicians and senior family members, adjusted their daily routine, and paid more attention to sleep and regular exercise (H-24, E-31, H-74, and A-37 in Table 4).

Additionally, the women with CHD believed that they played a crucial role in the growth process of their children and that they were closely connected to their children. Therefore, the women's consciousness over their health continued until they decided it was enough. After the first pregnancy of the participants, numerous factors affected their decision to get pregnant again, including the complications that occurred during the first pregnancy, physicians' evaluation of their health, and their self-evaluation of their health and the health condition of their children. The results revealed that after the participants experienced pregnancy, they understood the importance of regular follow-up visits and health maintenance (C-15 and G-27 in Table 4).

*Theme 3: Building self-worth from my baby*

The participants reported their perseverance and determination to achieve their goal. When physicians stated that pregnancy and childbirth were high-risk activities for them or recommended against pregnancy, the participants felt that if they took this advice, they would miss something in their lives. It was similar to having their rights deprived or being labeled as separate from ordinary people. Regardless of whether the participants perceived the effect of their CHD on their lives, they stated that they wanted to be indistinguishable from other mothers. Furthermore, they did not want their disease to affect their personal relationships and interactions with other family members. From the moment they confirmed their pregnancy, the participants prepared themselves for all types of challenges and did not want to give up, regardless of the number of adversities they would encounter. Regarding the risks of pregnancy and labor, the participants described the challenges and hazard level of their pregnancy.

The healthy birth of their child was critical for each participant. In addition to their feelings of concern for their child, the child's arrival served as a proof of their own value. As the participants saw it, when they understood and were willing to face the risks of pregnancy and childbirth, and when they finally became a mother, they proved to others that they could do what others thought they could not. The arrival of their child gave new value to their existence that allowed their life to remain meaningful. Other people may not be able to understand the goals and expectations that these women had during their suffering, but these women were able to enhance their self-value through the arrival of their child (H-20, B-16, and F-19 in Table 4).

*Theme 4: Adapting to postpartum life and adjusting priorities*

Most of the women with CHD focused on themselves before they became pregnant. After the conception, they began to imagine and construct a vision of how they would live and interact with their child in the future. However, their imagined life of being a mother was different from their actual life. Once a woman becomes a mother, she seldom has the time and space for her own life activities. Therefore, regardless of whether the participants were employed (i.e., full-time employment or full-time mother), they faced maternal role conflict. Poor quality of sleep and overfatigue affected their health, leading to cardiac discomfort and negative emotions. Nonetheless, the participants prioritized taking care of their child and ignored the discomfort caused by their disease (K-16 and B-8 in Table 4).

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**Table 3** *An Examplar for the Process of Data Analysis from Meaning Units to Theme.*

| Meaning unit | Category | Subtheme | Theme |
|---|---|---|---|
| "… Every time the doctor said that I had to exercise several times a week and go to the dentist to prevent tooth decay. The doctor would remind me every time I went back to the clinic, but I did not do it once …" (J-12) | Overlooking the influence of CHD on personal health | Lack of regard to CHD | Recognizing pregnancy risks |
| "Actually, I had not tracked my heart. I would not know how serious my heart condition was but that I was pregnant … Until I was pregnant and giving birth, the doctor explained my heart to me. He gave me a handbook with detailed information on it, so I really understood my heart condition." (D-26) | Incomplete knowledge of CHD | Lack of regard to CHD | Recognizing pregnancy risks |
| "Yes, I was not worried about my danger. I have been thinking about what to do with my child. I was afraid that my child would be hypoxic just like the doctor said. It would cause many major diseases in the brain. I have been thinking about this problem …" (G-17) | Worried about the baby's health | Uncertainties surrounding safety during pregnancy | Recognizing pregnancy risks |
| "We didn't particularly want to challenge. It's just that we would be disappointed at that time … It's not that we chose not have a child, but because we have been told that we can't have a child. We still have been disappointed …" (H-9) | Scared of losing the baby | Uncertainties surrounding safety during pregnancy | Recognizing pregnancy risks |
| "I felt that my physical health was unstable … I was not sure if I could bear the risks of pregnancy and childbirth. The degree of this risk was beyond my prediction, so I felt that pregnancy was dangerous for my life." (D-6) | Uneasy about unpredictable events during pregnancy | Uncertainties surrounding safety during pregnancy | Recognizing pregnancy risks |

CHD: congenital heart disease.
The underline: meaning unit.

The parenting attitude or concepts of an individual can be influenced by the parenting attitude or concepts of his or her own mother. Participants described their own mothers' experiences of caring for them. Because of CHD, their mothers paid more attention to them than they would have to a child without CHD and tried hard to protect them. The participants wanted to protect and care for their own children in the same way. Their own upbringing had a certain importance in the memory of the women with CHD; they perhaps adopted their mothers' child-rearing concepts and experience and transformed them into something of their own. Nevertheless, each participant had unique opinions, feelings, and expectations regarding the way their children should handle things and express emotions. In the worlds of these mothers, their children were the most important things in their lives (K-18, B-29, and F-30 in Table 4).

*Theme 5: Enjoying being a first-time mother*

The women with CHD realized that they were becoming a mother; this realization usually arrived when their fetus started to move or when the baby was delivered. When the fetus began to move, the expectant mother started to feel that there was a little life growing inside them and that the life needed her protection. Additionally, an amazing interaction occurred between mother and child; when the child exhibited behaviors that indicated his or her need for the mother, the mother felt that she was the center of the child's life. Throughout this process, the participants felt that they were needed by their child and considered the child's need and desire for their mother to be a gift from the child to themselves. Therefore, a strong desire to protect her child was generated. Consequently, the mothers were willing to lavish unimaginable love and care on their children. They hoped that they could record every moment that they spent interacting with their child; the child's growth record would be representative of the work that the mother had performed. The birth of the child brought a great sense of achievement and fulfillment for the participants. They had great expectations for their healthy babies. Equally, they were grateful and appreciative for the arrival of their babies. The women with CHD were thankful that their child was willing to enter the world and their life, granting them novel experiences and feelings. Such a state of mind differentiated the mothers with CHD from other family members and resulted in a close relationship between mother and child, causing their emotional bond and interactions to be more intense and profound (H-73 and D-17 in Table 4).

*Theme 6: Factors contributing to success in high-risk childbirth*

The participants experienced the processes of pregnancy, delivery, and child caring, and they expressed the importance of coordination between internal and external resources. The primiparous women with CHD believed in the professional evaluation and suggestions provided by their CHD medical team. However, the method and attitude that medical personnel chose to adopt when conveying decisions and suggestions could strongly interfere the feelings and opinions of the participants, thereby leading to differing opinions of the women with CHD when they

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**Table 4** *Identified Themes, Subthemes, and Quotes from the Interviews.*

| Theme/subtheme | Quotes from the interviews |
|---|---|
| Recognizing pregnancy risks | |
| Lack of regard to CHD | "That's right! That's why I said it wasn't planned. I didn't know how severe my condition was? Yes! Actually, it was really severe. I had the surgery at a really young age, when I was 6 years old. I didn't really understand my medical condition until I recently gave birth … I feel that I have better understanding of it now. I was given a booklet, which had a detailed explanation of the condition, including the classification levels you just mentioned …" (D-26) |
| Uncertainties surrounding safety during pregnancy | "I was quite worried during that time; I was worried that my baby would have the same medical condition as I do. Because my heart is slightly … slightly positioned to the right. That's right! I was worried he would have the same medical condition as me, and whether he would have a genetic disease. Dr. A told me that my child would be prone to genetic diseases and that my medical condition is likely to cause genetic diseases in my children, so I was quite worried. After I gave birth to my baby, I did send him for some medical examinations; he was examined by Dr. A and Dr. B … Of course I was worried; no parent wants their children to suffer." (I-12) |
| Performing self-care for health | |
| Desire to become a mother | "We have been discussing whether to be pregnant …. Anyway, I might have been too happy at that time,<br>Just tell him yes, I'm OK, I'm fine. At that time my physical condition was really good, and I didn't know why I believed in my situation, so I told him, just try it! Anyway, I think I would return to the clinic regularly." (H-24) |
| Proactive medical-care-seeking behaviors | "I did visit Chinese physicians for health promotion treatment. I still think that Chinese medicine and Western medicine are very different." (E-31)<br>"Because I wasn't sure exactly what kind of influence this medical condition has … like on pregnancy and overall health, and I was thinking, "Right, I just have to give birth first. About my condition … we'll see what happens." But after I gave birth, I realized that I wanted to be with him as he grew up! [chokes up]" (H-74) |
| The importance of an evaluation before conceiving | "I think the first priority is still consulting the doctor. If the doctor gives me the green light after an evaluation, I would ask the doctor if there're any precautions I should take … things like that. And you also need to be cautious during your pregnancy. You need to take extra precautions in everything you do. For example, when I was pregnant, my mother reminded me not to ride a motorcycle, because the roads in Taiwan are uneven, and riding a motorcycle on an uneven road would not do the baby any good. You must be careful in everything when you are on the way to becoming a mother." (A-37) |
| Reflecting on health during pregnancy and labor | "It's better not to get pregnant that I take the medicine. But doctor tells me to eat every day. If I want to get pregnant, I have to stop for at least half a year. Quitting the medication is also risky for me, but I really want to have a second child. I have talked to the doctor three times, and the nurse thinks I am too anxious …" (G-27) |
| Building self-worth from my baby | |
| The hope of not being treated differently | "Actually, I was just asking the question out of boredom. I asked if there was anything I could still do. And then I asked about more important things, and then I was asked about … I asked the doctor about the possibility of getting pregnant, and then … I was a bit regretful when I heard that, because I felt like I was already different from normal people." (H-20) |
| The most important decision in my life | "I just felt that I wanted to have children, and everything I did was because I wanted to have children, so I need to move in that direction! Frankly, sometimes I did feel that … I should just give up the idea of having children. But then again, I thought that was the only time I could work toward having children. If I waited until I was 40 or 50 years old, it would be impossible for me to have a child. That's why I felt I should work as hard as possible and see what happens. If my efforts were unfruitful in the end, I could at least say that I had no regrets. That's why I didn't give up throughout the whole process, and I ended up having two children (twins), one boy and one girl." (B-16) |
| The need to prove to myself that I can do it | "After I gave birth to my child, I felt like I had achieved something impossible. Because 8$^{th}$ months after I was born, I was diagnosed with double outlet right ventricle with transposition of the great arteries. Given the medical technology in the 1980s, this medical condition was basically incurable. At that time, the doctor told my mother that I could only wait for a heart transplant. That's why giving birth was like achieving something that others didn't think I was capable of. And I was the first person in my family to get married and have children, my family members were quite shocked by that. People in the older generation think that giving birth to an abnormal child means that the mother did something wrong in her previous life. Therefore, this is like a sort of vengeance for me." (F-19) |
| Adapting to postpartum life and adjusting priorities | |
| The meaning of freedom and responsibility | "Maybe mothers are … maybe you are biologically wired to wake up once you hear your baby cry. That's a maternal instinct. The father doesn't have it. He just sleeps so deeply. So I don't wake him up unless I have to attend to two babies (twins). Of course, he would help if I woke him up. But the truth is that I am the main caregiver, while he plays a passive assistant role." (K-18) |
| The inheritance and transformation of child-rearing experience | "I did think about what is most important to me. I thought about work, but then I thought, no, that's not mine, that belongs to the country. In the end, I feel that being a mother is the most important task for me right now." (B-29)<br>"For example, my classmates invited me to go hiking. Actually, I knew I shouldn't hike, but my mom made me go. During the hike I cried and vomited, but my mom followed behind me and said: "It's okay! Let's take it slow." I think the parents of children with CHD are very pitiful. They have a hard time, but I don't think it is necessary for them to be so negative. |

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**Table 4** (*continued*)

| Theme/subtheme | Quotes from the interviews |
|---|---|
| | Your child will be happy because you have to [pretend to] be happy, but in fact you are unhappy and your heart is not happy. (laugh)" (F-30) |
| The priorities of becoming a mother | "I was definitely swamped by my workload for a while … just taking care of the baby. Before giving birth, I just focused on carrying the baby; throughout the whole pregnancy, I just hoped to deliver the baby safely. So I didn't actually realize that there is a lot of caring work to be done after the baby is delivered and that I need to prioritize the baby all the time … Midnight was especially terrible, because the babies had an inverted day–night rhythm. Right, and I was really overwhelmed when both babies cried at the same time." (K-16) |
| | "Because both of going to work and taking care of my baby are so tiring, arrhythmia becomes the last consideration." (B-8) |
| Enjoying being a first-time mother | |
| The joy and affection of welcoming a child | "I felt that I had formed some sort of comradeship with the baby in my tummy, right from the beginning. It wasn't easy … so I think that my feelings toward my baby … they're kind of exceptional and special." (H-73) |
| Strengthening the sense of commitment to being a mother | "You would really … there was an invisible force that made you … you actually gave love to the child selflessly! This was quite unexpected." (D-17) |
| Factors contributing to success in high-risk childbirth | |
| Understanding and help from the employer | "My boss would let me take children to work. If my work is really over, I'll stay keep doing it, I won't insist that I have to walk on time. I am very grateful to the boss for his tolerance." (A-28) |
| Support and encouragement from family | "Without help from my family, it would have been hard for us to handle everything well. Help from parents made a big difference. When I was waiting for my delivery at around the 34th or 36th week, I was afraid that I'd deliver prematurely, so I went and stayed at a hotel in Taipei. If my sister hadn't kept me company, I would've been scared to go to Taipei alone." (E-18) |
| The overall professionalism of medical care | "The examination by Dr. A really eased my mind. That's why I said that sometimes the doctors' words really make you feel confident, more confident. Otherwise, you feel so frightened and scared, because you don't know what will happen in the future." (I-69) |

CHD: congenital heart disease.

were considering getting pregnant and delivering a baby. Helpful medical personnel and a positive medical care environment could lead to a sense of stability in the women with CHD; by contrast, subpar medical care services and environment could lead to confusion, anxiety, and uncertainties in the participants during their decision-making process. Throughout the whole process, the women with CHD hoped that their spouse or family members would be by their side, somewhat relieving their anxiety and fear. After they gave birth, the primiparous women with CHD were faced with various unfamiliar tasks and even a sense of fatigue. The understanding and help offered by the women's employers at this time relieved them from the dilemma of having to juggle work and family. Additionally, the company and assistance in taking care of the newborn offered by family members partially lifted the physical and mental burdens on the mothers that were caused by fatigue and the hectic situation; these efforts helped the participants tremendously in both the mental and practical aspects. The women desired support and company from their spouse most of all, followed by that from, members from their family and lastly member of their spouse's family; this indicates the significance and influence of the spouse during the process of pregnancy and child caring. In addition to depending on family relationships and familiarity, the women's preference of company was dependent on the role the women played in their family, their status in their family, the personality of family members, and familial relationships (A-28, E-18, and I-69 in Table 4).

## Discussion

The study results indicated that the themes could be divided into two categories: those related to chronology and resource utilization. The first five themes—namely recognizing pregnancy risks, performing self-care for health, building self-worth from my baby, adapting to postpartum life and adjusting priorities, and enjoying being a first-time mother—represent a dynamic and continuous process, whereas the theme factors contributing to success in high-risk childbirth link the preconception lives of the women with CHD to their postpartum lives and are considered representative of resource utilization. The lived experience of the new mothers appeared to embody the participants' personal traits and upbringing. The statements and behaviors of each participant revealed their distinct personality and demonstrated their uniqueness. Even though the life of the participants had been made different by their disease from that of their counterparts without diseases, the essence of the maternal role is the same for all. The processes of carrying and nurturing a child strengthened the maternal role in the primiparous women with CHD, resulting in apparently more intense mother–child interaction and expressions. The results of the current study are consistent with the maternal role theory proposed by Rubin [10] and Mercer [11].

The results related to recognizing pregnancy risks revealed the deficiency in the attention of the women with CHD toward their CHD. Clinical observation revealed that most of the women with CHD attended a follow-up session at the outpatient clinic before their conception or mid-gestation, which has been long since their last hospital visit for CHD. Similarly, Yeh et al. [17] reported that most patients with CHD overlooked the importance of long-term tracking after the age of 10 years. The leading causes of tracking cessation include personal factors, the lack of continuous care services, inconsistent in the professionalism of medical personnel, and the lack of a comprehensive referral program [17–19]. CHD requires long-term, regular, and consistent tracking. A systematically planned transition program for adolescents with CHD is needed to reduce the management risk of loss to follow-up and strengthen their self-care ability [3,17].

The age distribution of the participants in the present study was 22–46 years old. Furenäs et al. [20] conducted a survey of cardiac, obstetric, and neonatal complications with pregnancies in women with CHD and found that advanced maternal age did not seem to affect complication rate. In addition to the age above 35 years, higher mWHO class or other psychosocial factors influencing on the mothers may be taken into consideration. During pregnancy and

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labor, women with CHD are more likely than those without to sustain cardiovascular injury [7,21]. Despite their regular attendance of follow-up sessions, approximately 60% of young female patients with CHD did not discuss sex-related topics (e.g., pregnancy, labor, and contraception) with medical care personnel [22]. Aside from not realizing the importance of regular check-ups, women with CHD often overlook the possible impacts that CHD may have on pregnancy [19]. The lack of understanding regarding CHD as a medical condition and unplanned pregnancy can both increase the level of uncertainty and risk associated with the pregnancy of women with CHD. From the beginning of gestation to labor, negative emotions such as anxiety and uncertainty are consistently present. The possibility that any child would inherit CHD is one of the leading causes of negative emotions; stress and anxiety can affect the physical and mental health of women with CHD during the pregnancy [7,22–26]. This finding is consistent with that obtained in the present study.

The results regarding performing self-care for health revealed the desire of the women with CHD to become a mother as well as their worry and sadness caused by the possibility of not being able to do so. Such desire caused them to be unhesitant in trying to get pregnant [8]. Therefore, before their attempt to get pregnant, they visited hospitals to seek medical advice and used that advice as a basis for evaluating the health of any potential baby and whether they could overcome the risk associated with pregnancy [23]. At this stage, the women with CHD understood that an evaluation before conception was a crucial medical examination that could lower the risks of pregnancy and labor. Previous studies have also demonstrated that a comprehensive evaluation can predict the probability and potential severity of pregnancy complications to a relatively high degree of accuracy, and women with CHD can be given clear information on how to prepare for the pregnancy process and symptoms to monitor during the process [27,28]. In the present study, the participants proactively sought medical treatment and learned about CHD care, pregnancy, and health promotion behaviors, which was in stark contrast to their previously passive treatment-seeking behavior. This was consistent with the anticipatory stage in the maternal role theory proposed by of Rubin [10] and Mercer [29]. Additionally, Plutzer and Keirse [30] revealed that the focus of primiparous mothers mostly lies in the maintenance and enhancement of personal health. Preparations for the maternal role promote the abilities and protective mindset needed for maternal behaviors during pregnancy.

Traditional Chinese medicine is natural without the burden of chemical synthesis and mainly nourishes the body. Therefore, if patients use Western medicine with contraindications or strong side effects, Chinese medicine treatment may become an alternative to Western medicine treatment. Chinese medicine is more commonly used in Taiwan to nourish, invigorate, and adjust the body [31,32]. Some women who have experienced infertility, miscarriage, or want to have a smooth pregnancy may also turn to traditional Chinese medicine to recuperate their body. The participants in the present study are consistent with regulating the behavior of the body.

The maternal role requires a woman to protect her child from harm and from being threatened by her own medical condition [8]. In this study, this was exhibited in the attention the participants paid to their own health condition. Women with CHD do not wish to be seen differently by society but can feel differences between them and women without CHD. The limitations and differences experienced in their daily lives may have caused the participants to feel that their disease controlled their lives and caused them to crave recognition [33]. Pregnancy also poses a certain health risk for women. During this period, maternal resilience emerges. For the sake of their child, the participants had to stop their medications in certain circumstances, which is consistent with a qualitative synthesis of maternal resilience by Vallido et al. [9]. At this time, they identified themselves as a mother first and a CHD patient second.

The enjoying being a first-time mother theme indicated that emotional exchange is crucial to a healthy mother–child relationship [26]. The mother–child interactions that occurred after the child was born enriched the family life of the women with CHD. Compared with people from western countries, people from Asian countries express affection in more subtle and humble ways [34]. Asian mothers may not often verbally express their love and affection for their children, but they are responsive to the needs of their children. The participants with CHD in this study who gave birth considered their child a precious gift. To return the love that they received from their child, they devoted their affection, protection, and attention to their child without reservation; this was an exclusive relationship between a mother and baby.

Finally, the factors contributing to success in high-risk childbirth in the present study indicate the existence of three resources of social support: support from the family, employer, and medical care team. For women with CHD who are on their way to becoming a mother, apart from spousal financial and emotional support, spousal participation in the pregnancy and labor processes plays a critical role in providing the women with courage and confidence for the long journey [35]. Understanding from the employer can mitigate the time pressure problems faced by working women. As for medical personnel, they were providers of knowledge, suggestions, and guidance in the eyes of the participants. Suggestions from the medical care team affected the emotions of the patients. Excluding minor cases in which medical interventions and suggestions have resulted in stress, almost all relevant studies have indicated that the appropriate employment of medical resources improves the safety of patients and effectively reduces or prevents possible risk factors [28].

### *Limitations*

The sample in the current study included only primiparous women with CHD who were recruited from a single medical center and whose children were aged 6 months to 3 years. Therefore, the present results cannot be generalized to the whole female population with CHD. Because the participants of this study came from various counties and cities of Taiwan, the researchers left the choice of interview venue to the participants. Some of the participant brought her children along because no one was available to babysit. The interviews were sometimes interrupted because the participants needed to attend emergencies related to their children. This can be considered an environmental limitation of the current study.

## Conclusion

The findings of this study presented that the women with CHD reported a consistent set of core concepts regarding their process of becoming a mother for the first time. Six main themes related to the feelings and experiences of the women with CHD in becoming a mother for the first time were identified. These themes indicate that from the preparing for pregnancy stage, to the pregnancy and labor stage, and to the child-rearing stage, the women with CHD did not experience only a single emotion during the entire process. At every stage, they experienced the emotion cycle of worry, joy, fear, and ease. In other words, their emotions were complex and ever changing. Therefore, appropriate social support and intervention are necessary during this period. The findings provide relevant parties with better understanding of the emotional course in events experienced by women with CHD during their pregnancy. The

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results also indicate the importance and unique contribution of this study in the research area of women with CHD.

## Author contributions

Study conception and design: YTL, CWL, PFM and CWC; data collection: YTL and YMS; data analysis: YTL, PFM, YMS and CWC; manuscript drafting: YTL and CWC; and funding: CWC. All authors approved the final version for submission.

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## Conflict of interest

The authors declare that there is no conflict of interest.

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