

Congenital Heart Diseases: A Phenomenological Study of Parents' Lived Experience in Jordan

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Abstract: Congenital Heart diseases (CHD) are considered the most common severe congenital anomalies among infants. Present studies revealed that quality of life associated with long life caring process has been improved through understanding the parents' lived experience of infants with CHD. In Jordan, no studies were published to determine parents' lived experience. This present study is conducted to explore parents' lived experience of the child with CHD in Jordan.

This descriptive phenomenological study was conducted at Queen Alia Center for Cardiac Surgery in Royal Medical Services /Jordan, from February to April (2019). A sample of 11 parents of infants with CHD were invited to participate in a semi-structured recorded interview over 90 minutes. This interview utilizing Colaizzi' methods (1978) and extracting four thematic statements: "Fear of uncertainty and the unknown", "Mothers' fatigability in caring process", "Knowing alleviate anxiety, tension and stress", "Spiritualization and socialization being as helpful in coping process".

Recognition and enrichment of parents' knowledge using teaching programs or handouts were found to be useful. The advanced nursing role was helpful to parents during dealing with their challenges. Future studies are needed to further examine these findings and long term health related outcomes of this high risk group.

Keywords: Lived Experience; Parents; Congenital Heart Diseases; Descriptive.

INTRODUCTION

Congenital Heart diseases (CHD) are considered the most common severe congenital anomalies among infants followed by Neural tube defects and Down syndrome (WHO, 2019).

In the USA they affect 40,000 newborns or 1% annually (AAP, 2019) and 6.9 per 1000 births in Europe to 9.3 per 1000 in Asia (AHA, 2015).

The advanced medical and surgical techniques for treatment affected the prevalence rate and showed a dramatic increase in survival rate globally. CHD account for 4.2% of all neonatal deaths. Non-critical CHD survival estimates are as high as 95% survival to 18 years of age compared to lower estimates for critical-CHD survival predictions of 74% at one year and 69% at 18 years (CDC, 2018). The management of CHD depends on the types and severity of the defects, CHD is typically classified as mild-moderate or severe, cyanotic and non-cyanotic congenital heart defects. Gibbons et al. (2013) pointed out that the surgery may be postponed until the age of 3 to 5 years depending on the severity, while some patients need immediate operation.

In 2005, the American Stroke Association recommended to use the term "defect" instead of "disease" since only 8% are genetic causes and that the majority of causes were environmental exposures such as infections, chemicals, alcohol, drugs or gestational diabetes (AHA, 2015; Sullivan, 2016).

Health outcomes had been improved for congenital cardiovascular defects. In the USA, CHD hospitalization cost \$5.6 billion in 2009, with the highest cost account to hypoplastic left heart syndrome, coarctation of the aorta, and tetralogy of Fallot (CDC, 2018).

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Several studies reported that the level of stress, anxiety, and depression increase among parents living with a child with CHD (Lo'pez et al., 2016; Bevilacqua, Palatta, Mirante, Cuttini & Seganti, 2013).

Lo'pez and colleagues (2016) examined emotional distress, depression, and quality of life of mothers and fathers and between pre and postnatal diagnosis and showed that children's surgery decreased parents' hopelessness ($P < 0.04$). No significant differences were reported on other scales.

Jackson et al. (2018) reported that parents' coping mechanisms can be started with non-productive coping approaches like denial process or productive social support with others through the caring process. Health providers can support parents and help them to cope with the presence of stressors.

With this context, an analysis of a systematic review of 25 studies identified that families with less psychosocial support may be risk for greater psychological suffering and less well-being over time. Familial factors such as cohesiveness and adaptive parental coping strategies are necessary for successful parental adaptation to their child. (Jackson, Frydenberg, Liang, Higgins and Murphy, 2015).

Clearly the topic of CHD is well covered in regard to the high mortality and morbidity globally and there is a clear shift of survival into adulthood (AHA, 2019). However, in Jordan, one study determined the incidence of CHD retrospectively in Jordanian children born at Jordan university hospital from 2007 until 2014 and the study revealed that CHD was presented about 12.3/1000 Jordanian live births which was slightly higher than the global incidence. (Ammouri, Ayoub and Tutunji, 2017).

On other retrospective descriptive study in Jordan in the Prince Hashem hospital in Zarqa; Amro (2009) showed the pattern of CHD over a period of 2005 to 2007 for child less than 18 years referred for echocardiography (ECHO), 74% of the children had non-cyanotic CHD ; ventricular septal defects (VSD) were the commonest lesion founded, while tetralogy of Fallot (TOF) were the commonest cyanotic heart defects.

Based upon the extensive literature review on CHD and of parent caregiver we devised the following study for parental support of this high risk group, Furthermore to the best of the researcher's knowledge, there were no published studies that investigated the parents perspectives of being responsible for the care of a baby with CHD.

METHOD

Study Design

This study utilized a descriptive phenomenological design with purposeful sampling, semi-structured interviews that showed the purpose of this study using questions guide; the proposed method of analysis is using the common content thematic analysis of Colaizzi that was best for this study regarding the analysis.

Besides that, the Institutional Review Boards at Mutah University and Royal Medical Services approved the research proposal to ensure the ethical consideration regarding this study. Furthermore, each participant was asked to assign consent form and voluntary participation in the study along with their agreement to use tape recording in the interview; they were free to stop or withdraw the interview at any time, also they were ensured that all information will be with anonymity and confidentiality.

Study Setting

The study was conducted in a military institution of the Royal Medical Services (RMS) in Amman – Jordan at Queen Alia Center for Cardiac Surgery/ Royal Medical Services

(RMS). This institution provides health care for a wide range of children needing pre and post-surgical care for CHD diagnosis.

Sampling

Recruitment took place on a children 'cardiac ward between February 2019 until April 2019, a purposive sampling involved enrollment of those who met the criteria of this study. Inclusion criteria were: both parents over 18 years of any religion, they were be able to speak Arabic and they received their child at least 8 hours after surgery; the time needed for child's stabilization physiological condition and alleviate the parents' anxiety level. Parents who weren't willing to participate or prepared their child for the operation were excluded.

The exact sample size for phenomenological studies is difficult to be clarified. Creswell (2013) proposed that the sample size should be between 5 and 25 participants. The saturation was reached in this study on 11th parents, from the 8th parents the themes were founded despite that we reach 11th parents in order to confirm. Three of the experienced staff nurse, who had a had a minimum of 6 years of experience in this practical field helped the researcher to give the impression of data saturation.

Data Collection

Interviewing is the main root of data collection for phenomenological studies (Colaizzi, 1978; Patton, 2002). Phenomenological interviews highlight the uniqueness of each interview, in which interviewers treat each participant as a unique individual, not as part of enduring hypothetical sampling.

The interview was initiated by the researcher for each participant in closed room with no interruption during interview time, accompanied with their child as they preferred. The demographic data were obtained for parents and their child followed by interview question that lasted maximum 90 minutes, the interview started with preparatory statements based on the study purpose that focused on the phenomenon of interest.

The statement was "I am interested to know about experiences with your child regarding feelings, obstacles and concerns".

It is followed by the study questions; "Can you describe your experience during caring of your children with CHD?", "What are your major concerns regarding the care of your child?", "How has this affected you and your entire family (socially, emotionally and physically)?", "How this experience affected your marital relationships?", "What's your major coping mechanism in dealing with child with CHD?"

Also, the interview was followed up by questions such as: "Please tell me more about it", "what's your perception about them", "Please give me an example". Five of parents were interviewed together as couple while six mothers were interviewed alone; the exact significant sentences' were founded mainly during face to face recorded interview .

Whereas the second interview that was conducted by telephone helped researcher to follow up the validity of meaning after discharge. However the participants were so pleased to share the second interview. This helped researcher to immerse and find the essence of their feelings and concerns.

Data Analysis

The concept of "bracketing" comes from Husserl's epoché (Englander, 2014). It means that the researcher deals with the data as it appears in natural context without the researcher personal impression and preexisting presuppositions of the situation. Spiegelberg (1965, 1975) identified a three-step process for descriptive phenomenology: 1) intuiting, (2) analyzing, and (3) describing.

This analysis was done according to the proposed method of Colaizzi (1978) which shows the underlying content thematic analysis of this study. First, the phenomenon of interest was described with the preparatory question and primary interview question. Then participants' descriptions of the phenomenon were assembled by the researcher. After reading all participants' descriptions, the researcher returned to the original record, extracted significant statements, and then tried to conclude the meaning of each major statement. Finally, the

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researcher returned to the participants for validation of the description and if new data were revealed during the validation they were incorporated to the complete description

Trustworthiness

To enhance trustworthiness, the researcher utilized the strategy of Lincoln and Guba (1985). This strategy is an accepted approach for the qualitative method, and it uses terms that articulate phenomenology (Shenton, 2004; Creswell, 2013). This strategy contains four main aspects to demonstrate trustworthiness in the qualitative research; credibility, dependability, confirmability, and transferability which are discussed below under separate headings.

Credibility

It is one of the most important factors in establishing trustworthiness. This deals with the inquiry in which there is a similarity between the findings (themes) and reality (Shenton, 2004).

The following activities were conducted to ensure that the experiences of participants were described and analyzed subjectively.

A recognized methodology of data collection procedures was adopted from previous successful studies that are similar to the present study in the interview questions as well as the data analysis method (Giorgi, 1985). The study was strengthened by establishing a good connection with participants from the onset of the interviews and their willingness to be honest. Additionally, we used staff debriefing methods that included sharing the findings, explanations, and feedback through the data analysis process. These methods enhanced credibility.

Dependability

Once credibility is established, the dependability of the findings is accomplished (Lincoln and Guba, 1985). Dependability can be established by auditing research as it is in progress entitled "audit trail" in the study report. In this study, dependability was demonstrated through documenting changes in notes and reflexive journal.

Moreover, a clear, thorough, and detailed description of the research process, methods used in gathering and analyzing data, and comprehensive reporting of findings were performed. This may be achieved through the use of "overlapping methods" or triangulation. In the present study the face to face, individual interview was the only selected method for data collection. It is considered the most appropriate strategy that can serve the purpose of phenomenology qualitative research (Streubertand Carpenter, 2011).

The researcher had conducted all face to face interviews with the patients to make a better understanding of the phenomena in hands and prevent any further bias.

Confirmability

A key criterion for confirmability is the extent to which the researcher conceal his or her predisposition. Researchers declared the beliefs underpinning decisions made and methods adopted during the research process. The researcher declared the reasons for trading off one approach to another and weaknesses in the applied approach as described by Shenton (2004).

Confirmability in this study was enhanced by reviewing the research process coding and analyzing by experts in nursing and qualitative research (Bawadi et al., 2009).

An extensive methodological description enables the reader to decide to what extent the data and themes emerging from it may be believable. This reflects the process of "audit trail", which allows any observer to trace the entire process of the research step-by-step through a full description of researcher decisions and approaches followed (Shenton, 2004; Creswell, 2013).

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Dependability and conformability of the current research study were fostered through presenting the readers with full and in-depth design descriptions so, the researcher will be able to judge the effectiveness and integrity of the research practices (Creswell, 2013).

Transferability

Transferability means the generalizability of findings (Streubert and Carpenter, 2011) through which study findings apply to other similar situations (Shenton, 2004). Lincoln and Guba (1985) suggested that the investigator is committed to provide adequate contextual information about the fieldwork sites to enable readers to make such transfer (Shenton, 2004; Creswell, 2013; Bevan, 2014).

In this study, transferability was guaranteed by providing contextual data about the study in terms of participants, setting, data collection, and analysis procedures. Furthermore, how codes and themes were generated. A reflexive report of the research process which provides readers with additional information further enhance their ability to judge the applicability of the findings.

RESULTS

This section presents the child with CHD characteristics and parent's characteristics. Also the findings in terms of forwarded themes, and the most revealing participants' quotes for theme and general description.

Table1

Child with CHD Characteristics	(%)
Age	
< 6 month	27%
> 6 - 1 years	55%
(1-6) years	18%
Gender	
Male	55%
female	45%
Medical diagnosis	
VSD (ventricular septal defect)	37%
ASD (atrial septal defect)	18%
PDA(patent ductus arteriosus)	27%
Single ventricle	9%
TOF (tetralogy of Fallot)	9%

Table2

Parent 's Characteristics	(%)
Parents level of Education	
Mothers	
Less than Bachelor level (high- level school).	18%
Bachelor level.	73%
More than Bachelor	9%
Fathers	
Less than Bachelor level (high- level school).	40%
Bachelor level.	60%
Insurance Type	
Military	36%
Civilian	64%

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Employment	
Mothers	
Employed	45%
Not Employment	55%
Fathers	
Employed	75%
Not Employment	25%

The description of CHD patient's demographic characteristics showed that the majority of CHD enrolled were 55 % between 6 months to one year of age and were also male infants, mostly diagnoses with cyanotic CHD (37% VSD, 27% PDA and 18% ASD). Concerning the demographic characteristics of parents, 73% of mothers hold bachelor's degree among which 45% were employed mothers, comparing fathers; 60% held a bachelor's degree and 75% were employed. Also, 64% of the patients had civilian insurance.

Analysis of generated data using Colaizzi (1978) revealed five major themes; "Fear of uncertainty and the unknown", "Mothers' fatigability in caring process", "Knowing alleviate anxiety, tension and stress", and "Spiritualization and socialization being as helpful in coping process".

1. Fear of uncertainty and the unknown: most of interviewed couples were shocked in the emergency department when the doctor had requested ECHO for their infants who were complaining of respiratory bronchiolitis. That a very stressful moment of uncertain diagnosis and unknown cause.

One couple said "we didn't expect his problem of CHD, we were shocked when the doctor said that" Also, one mother said, *"I have three healthy children with no history of heart disease, how did my son get this?"* Other couples said: *"we didn't know the exact cause until now; can you tell us if we would have another baby with the same condition?"*

One father said: *"It was a shocking moment when doctor said your child had a big VSD, and he needs a surgery as soon as possible"*

All patients in this study revealed that the surgery was a frightening experience that they had disturbed feelings when the child was undergoing the surgery. One mother said: *"Two weeks in the CCU after the surgery, not knowing if she would die or not"* Another mother said: *"It was a fearful situation, if the surgery will be successful or not and my baby live, it was difficult time for me and his father wondering if my child will tolerate the operation"*

2. Mother fatigability in the caring process: the mothers were the main caregiver in this study, and some of them they missed their work, or have other children at home.

One mother said: *"I had missed my work approximately two weeks, I need grandma to stay with my child tomorrow, I need more days off my work"*

In addition to that, another mother said: *"I'm thinking every time of my baby's surgery, I'm responsible for three other children at home – I was completely distracted, we had to care of all, Allah will support me"*

3. Knowing alleviate anxiety, tension and stress: mostly all of the parents trusted the knowledge had been received by doctors or informed by health care providers; most of them need to know the risk and benefits of the surgery. Most information help them to make the operation decisions.

One of the parents explained: *"The doctor informed us that the operation has a 90% success rate, thus we were positively encouraged to do it, and we depend on Allah at all"*

Another mother said *"It is alleviated some of my stress when the doctor told me about other successful operation"*

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On the other hand, one mother said: *"Doctors outside this center had told me that my child will have major surgery and it might have a complication that made me mad, but the doctors in this center have calmed me down through discussing the condition, now my baby has completed the surgery Ahamdo -lelAhha"*.

In addition, one mother had previous experience with a child who was diagnosed with CHD prior to the current situation. Her past experiences helped her to cope better with this child's condition and hospitalization, she said: *"if you see me not crying, it doesn't mean that I'm very well. I know everything about the case; I lost one child before who had the same condition"*

4. Spiritualization and socialization being as helpful in coping process: notably, two ways were found to help parents in their coping process; spiritualization and socialization.

Most of them they were working as a couple to deal with their child situation, in addition to that all of them were Muslims and they believe in Allah to have mercy on them and their child. However, some showed that previous experiences of the same circumstances helped them to accept what was happening.

DISCUSSION

The feelings of parents with children undergoing heart surgery or post-surgery are not similar. When having a child with CHD undergoing heart surgery, parents had doubts about uncertainty the success of surgery, possibility of dying, complication of cardiac surgery. This part was similar to (Harvey, Kovalesky, Woods and Loan, 2013) who explored the lived experiences of eight mothers of infants with moderate to severe CHD needed heart surgery prior to their first year; mothers were feeling of intense fluctuating emotions, dealing with the unknown, facing the possibility of death, and finding the meaning of spiritual connection.

However, according to Allen and Jensen (1990), understanding the meaning of individuals' experience with health as well as illness is crucial in nursing research to promote health overall. Nurses can understand parents with different cultural and religious backgrounds. They can help them deal with different fluctuating emotions according to their child's condition. Lisanti et al. (2018) considered that the psychosocial aspect of parents is an essential part in the coping process.

In addition, the study reveals that parents' experience extended their responsibilities to understand and contribute to what they need and seek the knowledge that helps them to alleviate their suffering. Nurses, also, are trained to convey their responsibilities as properly as possible to enhance the health-related outcomes (McKechnie, 2012).

Knowing this, healthcare providers support parents by involving them in the caring process. This includes discussing or teaching health education programs related to their child's condition, and applying handouts before and after the surgery.

However, previous studies pointed out regarding prenatal counseling as another aspect that can reduce anxiety, especially for fathers during mother's pregnant time (Pinto, Weng and Sheng, 2016).

The researcher identified that mothers experience fatigability from playing multiple roles.

This finding is similar to the findings of the study conducted by (Simeone, Platone, Perrone, Marras, Pucciarelli, Benedetti, and Gargiulo, 2018) that highlighted the lived experience of parents whose children were discharged to home after cardiac surgery, the main themes emerged after the analysis were "happiness and uncertainty" and "chronic psychophysical fatigue". It's important to understand the mother's multiple roles in the caring process to promote a holistic approach to enhance the coping mechanisms.

CONCLUSIONS AND CLINICAL IMPLICATIONS

Understanding the parents' lived experiences helped to support them before, during and after conducting the heart surgery. Therefore, nurses can formulate an educational program session, handouts to connected parents'

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scientific information and elaborate more on interventions that support health especially in resuscitation time and along with the child growth and development process in the future.

Furthermore, nurses should take into consideration applying a holistic approach as ideal as their knowledge to promote health-related outcomes of parents with a child with different cultural and religious backgrounds and parents with multiple roles.

Further to the concern, future studies are needed to examine long term outcomes after CCU discharge for patients with CHD and their families; and to investigate further parental concerns at home or in the community resources.

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