

ORIGINAL ARTICLE

Impact of Caring for Children with Congenital Heart Disease on Nurses' Lives: A Qualitative Study

Konjenital Kalp Hastalığı Olan Çocuklara Bakım Vermenin Hemşirelerin Yaşamlarına Etkisi: Nitel Bir Çalışma

AYşe Ay¹, İÇim Ercan Koyuncu¹, AYlin Günay²

¹Department of Pediatric Nursing, Başkent University Faculty of Health Sciences, Ankara, Turkey

²Department of Surgical Nursing, Başkent University Faculty of Health Sciences, Ankara, Turkey

Abstract

Objective: Advances in technology have improved survival rates for children with congenital heart disease (CHD), leading to additional surgery and longer hospital stays. Nurses are essential healthcare professionals involved in these challenging processes. This study aimed to explore the impact of caring for children with CHD on the lives of nurses.

Method: A qualitative-descriptive research design was employed. The study was conducted with 15 nurses caring for children with CHD at a foundation university hospital in Turkey. Data were collected using a "Demographic information form" and a "Semi-structured interview form" through face-to-face interviews. Nurses were asked to discuss the positive and negative effects of caring for children with CHD on their own lives. The interviews were recorded and professionally transcribed. Two researchers thematically analyzed the transcripts using MAXQDA. The study was conducted using the Consolidated Criteria for Reporting Qualitative Research criteria.

Results: The average age of the nurses was 30.53±5.14 years, and 73.33% had more than 5 years of experience caring for children with CHD. The results of the individual interviews revealed five main themes and 14 subthemes. These main themes are (i) Strengthening knowledge and skills, (ii) Interaction with the child, (iii) Psychosocial empowerment, (iv) Emergence of negative impacts, and (v) Overcoming challenges in professional life.

Conclusion: Caring for children with CHD positively and negatively impacts nurses' lives. To mitigate the negative effects on nurses, providing physical and psychological support and empowerment are crucial.

Keywords: Child, nursing care, congenital heart disease, qualitative research

Öz

Amaç: Teknolojideki ilerlemeler konjenital kalp hastalığı olan çocuklarda sağ kalım oranlarını yükselmekte, bu durum ise ek cerrahi ve uzayan hastane yatışlarını beraberinde getirmektedir. Konjenital kalp hastalığı olan çocukların bakımından sorumlu olan hemşireler, bu zorlu süreçlere dahil olan sağlık profesyonelleridir. Bu çalışmada konjenital kalp hastalığı olan çocuklara bakım vermenin hemşirelerin yaşamlarına etkisini incelemek amaçlanmıştır.

Yöntem: Çalışmada niteliksel-tanımlayıcı araştırma deseni kullanılmıştır. Türkiye'de bir vakıf üniversitesi hastanesinde konjenital kalp hastalığı olan çocuklara bakım veren 15 hemşire ile araştırma yürütülmüştür. Veriler "Tanıtıcı bilgi formu" ve "Yarı yapılandırılmış görüşme formu" ile yüz yüze görüşme tekniği ile toplanmıştır. Hemşirelerden konjenital kalp hastalığı olan çocuklara bakım vermenin, kendi yaşamları üzerindeki olumlu ve olumsuz etkilerini tartışmaları istenmiştir. Görüşmeler ses kaydına alınmış ve profesyonel olarak yazıya dökülmüştür. Transkriptler MAXQDA kullanılarak iki araştırmacı tarafından tematik olarak analiz edilmiştir. Araştırma nitel çalışmaların raporlanmasında kullanılan Nitel Araştırma Raporlama İçin Birleştirilmiş Kriterleri doğrultusunda yürütülmüştür.

Bulgular: Hemşirelerin yaş ortalaması 30,53±5,14 yıl ve %73,33'ü beş yıldan fazla konjenital kalp hastalığı olan çocuğa bakma deneyimine sahipti. Bireysel görüşmeler sonucunda 5 ana ve 14 alt tema belirlenmiştir. Bu ana temalar şunlardır: (i) Bilgi ve becerilerin güçlenmesi, (ii) Çocuk ile etkileşim, (iii) Psikososyal güçlenme, (iv) Olumsuz etkilerin ortaya çıkması ve (v) Profesyonel yaşamdaki zorlukların üstesinden gelmek.

Sonuç: Bu çalışma, konjenital kalp hastalığı olan çocuklara bakım vermenin hemşirelerin yaşamları üzerinde hem olumlu hem de olumsuz etkileri olduğunu ortaya koymuştur. Konjenital kalp hastalığı olan çocuklara bakım vermenin hemşireler üzerindeki olumsuz etkilerini azaltmak amacıyla, hemşirelerin fiziksel ve psikolojik açıdan desteklenmesi ve güçlendirilmesi büyük önem taşımaktadır.

Anahtar Kelimeler: Çocuk, hemşirelik bakımı, konjenital kalp hastalığı, nitel araştırma

Corresponding Author:

Ayşe Ay, ayse0526@gmail.com

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Introduction

Congenital heart disease (CHD) is an anomaly that often leads to neonatal mortality. According to the American Heart Association, the incidence of CHD is approximately 12.3 per 1,000 live birth (1). In Turkey, the annual number of infants born with CHD ranges from 11,000 to 17,000 (2). Advancements in technology and surgical expertise have significantly improved the survival of children with CHD (1). Despite improvements in survival rates, the recovery process often involves additional surgeries or medical interventions, resulting in extended hospital stays among children (3). Although it is expected that these children will fully recover and return home, some succumb to complications despite advanced medical and surgical interventions. Consequently, healthcare professionals address the physiological needs of children and provide emotional and psychosocial support to both children and their families, increasing caregiving responsibility (4).

The care of children with CHD in hospitals is heavily dependent on the crucial role of nurses. It has been reported that nurses are among the leading healthcare professionals in helping to establish positive caregiving strategies in families of children with CHD (5). Nurses have constant interactions with children and their parents, and as a result, they frequently witness challenging moments, such as children enduring pain and distress (6). In addition to providing care for critically ill children, nurses are responsible for making critical care decisions and supporting families with challenging choices, which have a significant impact on their professional and personal lives (5,7).

Nurses caring for children with CHD are at risk of experiencing physical and psychological health effects, including burnout, compassion fatigue, secondary trauma, and moral distress (5,8). These experiences can impact their professional and social relationships, job satisfaction, and motivation, potentially leading to increased absenteeism and a decline in the quality of care provided (8,9). Recent studies have highlighted similar challenges internationally. For instance, Bagnasco et al. (9) found that burnout rates among pediatric cardiology nurses were significantly higher in countries with limited staffing and resource allocation than in countries with robust support systems. Tito et al. (10) found that symptoms of tension, irritability, and anxiety were common among pediatric cardiology nurses, emphasizing the need for protective measures for their mental health.

The well-being of health professionals directly affects patient care, especially when caring for children with CHD.

Main Points

- Caring for children with congenital heart disease fosters nurses' professional growth and resilience.
- Emotional bonds with children can bring fulfillment but also lead to compassion fatigue and exhaustion.
- The demanding nature of the work results in physical strain for nurses.
- Institutional support, mental health services, and team collaboration are crucial for managing these challenges.

It was demonstrated that the skills of pediatric cardiology nurses were associated with fewer complications following pediatric cardiac surgeries (11). By creating a healthy work environment for these nurses, they can better identify issues early and provide thorough disease management (12). Recent evidence indicates that supportive supervision and access to counseling services effectively mitigate compassion fatigue and enhance resilience in pediatric cardiology units (13).

However, there is limited knowledge about how increased caregiving burden, compassion fatigue, and mental health issues impact nurses' lives. This study aims to fill these gaps and identify specific nurses' needs for organizational support, motivation, and stability. The primary focus here was on examining how caring for children with CHD influences the lives of these nurses.

Material and Method

Study Design

In this study, a phenomenological qualitative research design was used to reveal, understand, and conceptualize the subjective experiences of nurses more deeply because of the limited resources in the literature regarding the impact of nurses caring for children with CHD on their lives. The researchers adhered to the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist to ensure the accuracy and precision of their qualitative study.

Study Setting

This study was conducted within the pediatric cardiology clinic of Başkent University Ankara Hospital Hospital, which serves 400 pediatric cardiology patients annually in Turkey from March 1, 2024, to June 1, 2024. The Başkent University Ankara Hospital Pediatric Cardiology Department, which is a center for cardiac referrals from all over the country, was considered a suitable parameter for this study.

Selection and Recruitment of Participants

A purposive sample was used to obtain in-depth information on the characteristics of information-rich and dense cases. In qualitative analysis, purposive sampling is commonly employed to identify and select particularly informative participants, thus optimizing the available options (14). The study sample comprises 15 nurses. The participant's average working time with pediatric cardiology patients was six months, aged 18 or older, willing to participate in the study, and knew the Turkish language. Nurses were contacted and invited to participate in the study, and interviews were conducted by planning the appropriate time and place for the participants.

Ethical Considerations

This study was approved by the Başkent University Medicine and Health Sciences Research Board (date: 06.02.2024, no: KA24/62) and was approved by Başkent University Hospital

Nursing Directorate Services. This study was conducted using the Principles of the Declaration of Helsinki. The purpose of the research was explained to the nurses before the study. The “informed consent form” prepared by the researchers was read to the participants before the interview. In this form, nurses were assured of the confidentiality of their identities and voice recordings. After the nurses were informed about the purpose and methodology of the study, verbal and written consent was obtained. Participants were informed that they could withdraw from the study without reason. Confidentiality and anonymity were upheld through anonymizing data and its secure storage, which were accessible solely to the research team.

Data Collection

The study sample was determined based on theoretical saturation, which indicates the point at which data collection yields sufficient detail for thorough analysis. The researchers iteratively assessed the data to achieve theoretical saturation until no new information emerged and all relevant concepts were fully developed. Data collection concluded after reaching this saturation point, as indicated by the absence of new information or codes (15,16).

The researchers (AA, İEK) established the criteria for including eligible nurses in the study. They held meetings with potential participants to ask questions about the study and obtain informed consent. The following consent, interviews were scheduled. Before the interviews, the participants completed a questionnaire to provide sociodemographic information, including age, gender, educational level, and length of employment. This information is summarized in Table 1.

The data were collected through a semi-structured, in-depth interview. In-depth individual interviews were preferred for this study because they are suitable for exploring personal experiences, discussing sensitive topics, minimizing

group influence, and uncovering complex issues (17). The interviews were conducted in a designated room within the pediatric cardiology service, which was chosen for its environment in which participants could speak freely. This room provided a quiet space for recording and minimized distractions. A single researcher (AA), a female academic from the pediatric nursing department with prior qualitative research experience, conducted all the interviews. There was no pre-existing relationship between the researcher and the participants; each participant met the researcher and was informed of the study objectives during the interview.

The data collection phase of the study ended when data saturation was reached, as indicated by the receipt of similar responses from the participants. The sample consisted of 15 nurses who met the inclusion criteria. The interview duration ranged from 30 to 60 minutes, and all sessions were recorded using a device with audio recording capabilities. Each participant was asked to explain their feelings and experiences regarding the impact of working with pediatric cardiology patients. Research data were collected using the “Semi-structured Interview Form” developed by the researchers in line with the relevant literature review (5,7). The researcher was interviewed using semi-structured questions. The semi-structured questions were designed to deeply examine the impact of caring for children with CHD on the lives of nurses and to guide the participants. The interview questions are presented in Table 2. Following the observation of the entire process, the researcher posed supplementary questions and requested further clarification while documenting significant non-verbal cues (e.g., facial expressions, tone of voice, gestures) to mitigate potential errors. Additionally, to address possible issues with audio recordings, such as low batteries or volume inconsistencies, the researcher meticulously recorded the interviewees’ responses. All interviews were transcribed, and thematic analysis was conducted to evaluate the recordings.

Rigor and Trustworthiness

This study applied the concepts of sensitivity to context, rigor, transparency, and impact as outlined by Yardley (18). We achieved sensitivity to context by using verbatim questions, amplifying participants’ voices, and allowing

Characteristics	Mean ± SD	
Age	30.53±5.14	
Working years	12±3.85	
Working years with children with CHD	9±4.16	
	n	%
Marital status		
Married	9	60%
Single	6	40%
Educational level		
Bachelor’s degree	11	73%
High school	4	27%
Status of CHD training	0	0%

SD=standard deviation, CHD=congenital heart disease

What is it like to care for children with CHD?
How has caring for children with CHD changed your life?
What are the positive effects of caring for children with CHD?
What are the negative effects of caring for children with CHD?
Considering the effects of caring for children with CHD on your life, what are your expectations regarding the care and treatment process?

CHD=congenital heart disease

readers to trace their interpretations. Our interviewer, Dr. AA, a female researcher with a PhD in nursing and experience in pediatric cardiology, enhanced the trustworthiness and rigor of our qualitative analysis. She fostered a relaxed, open atmosphere through open-ended questions and reflexivity to mitigate bias. Dr. AA took notes, observations, and experiences to understand the study's context better, enrich the collected data, and contribute to the analysis process. Participants' reactions, gestures, facial expressions, and other notable elements were also recorded in the interview field notes. All participants provided their consent to participate in the study. Dr. AA was the sole mediator of the interviews to ensure compliance. The three researchers independently identified the primary themes and subthemes and engaged in discussions until they reached a consensus, ensuring the quality and reliability of the findings. We also extracted direct quotes from the interviewees' responses.

Statistical Analysis

Interviews were recorded using a voice recorder and were meticulously transcribed verbatim by two independent researchers (İEK and AG). The researchers listened to the recordings multiple times to ensure accuracy and consistency in the transcriptions. The transcribed data were subsequently imported into MAXQDA software (version 2020) for coding and thematic analysis. This approach, grounded in the frameworks of Braun and Clarke (19), is a widely accepted method for identifying, analyzing, and interpreting patterns in qualitative data. To enhance the reliability of the analysis, several steps were implemented (19): (i) one researcher (AG) initially organized the raw data and employed MAXQDA software version 2020.2.2 for coding and analysis; (ii) the research team (AA, İEK, AG) collaboratively examined and refined the codes, subthemes, and their definitions until consensus was reached; (iii) codes were consolidated into overarching thematic categories, ensuring data saturation; (iv) the identified themes underwent validation through peer review by a multidisciplinary team comprising physicians and nurses; (v) the first author conducted a comprehensive review of the thematic structure; and (vi) all data were synthesized to draft the final report. In the final stage, the researchers collaboratively reviewed and refined the themes, subthemes, and associated descriptions, resolving any discrepancies in the definitions through consensus. They determined that data saturation was achieved by organizing related themes into broader themes. The team reached an agreement on the finalized themes, culminating in the development of a core framework or theory that synthesized the key insights derived from the data. After the themes and subthemes were finalized, the participants were invited to review and confirm the findings. All participants endorsed the identified themes and subthemes without requesting modifications or providing additional feedback.

Results

Fifteen nurses with experience caring for children with CHD participated in the study. The average age of the participants was 30.53 ± 5.14 , and most (73%) had a bachelor's degree. The mean professional experience of the participants was 12 ± 3.85 years, while the mean experience in caring for CHD patients was 9 ± 4.16 years. The detailed characteristics of the nurses are summarized in Table 1. The findings of this qualitative study revealed that nurses caring for children with CHD had positive and negative impacts on their lives. Our analysis revealed five main themes describing these impacts in their life: (i) Strengthening knowledge and skills, (ii) Interaction with the child, (iii) Psychosocial empowerment, (iv) Emergence of negative impacts, (v) Overcoming challenges in professional life. All main themes and subthemes are presented in Table 3.

Theme 1: Strengthening knowledge and skills

Our findings revealed that nurses caring for children with CHD strengthened their professional knowledge and skills. Nurses expressed that they felt robust, well-rounded, and skilled because they faced many challenging experiences during their professional experience. This theme included three subthemes: being a person to be consulted, gaining self-confidence, and giving meticulous care.

Being a person to be consulted: The nurses stated that their relatives had consulted them, especially regarding heart diseases. A nurse who had been caring for children

Themes	Sub-themes
Strengthening knowledge and skills	<ul style="list-style-type: none"> - Being a person to be consulted - Gaining self-confidence - Giving meticulous care
Interaction with the child	<ul style="list-style-type: none"> - Development in the approach to pediatric patients - Strengthening communication with the family - Avoidance of communication
Psycho social empowerment	<ul style="list-style-type: none"> - Practicing patience - Understanding the value of life
Emergence of negative impacts	<ul style="list-style-type: none"> - Afraid of having a sick child - Reflection of the emotional burden in daily life - Despair toward recovery - Physical disorders
Overcoming challenges in professional life	<ul style="list-style-type: none"> - Team collaboration - Institutional support

with CHD for many years expressed the complex feelings she experienced when her friends' children were diagnosed with CHD as a result of her referral in the following words:

"I had friends' children whom I referred and unfortunately diagnosed with CHD as a result. However, because of this, they started treatment early. It may be a bad situation, but I feel lucky to work in this department. I have benefited my friends, relatives, and children (N5)."

Nurses felt themselves as robust, well-rounded, and competent when they were consulted. Two nurses also expressed this situation as follows:

"I am the first person my friends want to consult. I see myself as a superhero in such situations (N3)."

"Because it is an exceptional department, people with children ask questions." Sometimes, if I notice an abnormal situation, I can refer the patient to a doctor. We can be a source of information for people. It makes me feel professionally robust and competent (N12)."

Gaining self-confidence: The nurses stated that providing care for children with CHD was a challenging experience. However, they also noted that their critical decision-making abilities, knowledge, and skills underwent significant growth as a result of this demanding experience, empowering them to make crucial decisions in their practice. Consequently, they reported increased self-confidence and were ready to care for patients in various clinical settings. The nurses expressed their views as follows:

"Nursing is a profession that requires sudden decisions. I think that when I care for a child with CHD, I can care for all patients. I have attained significant self-confidence, and my knowledge and skills have increased a lot (N8)."

"The experience of caring for these patients has significantly increased my self-confidence. Seeing patients walking healthily and attaining control provides a source of encouragement and reinforces self-confidence and motivation (N11)."

"I find that working in a specific field, such as pediatric cardiac surgery, boosts my self-confidence because I witness patients recovering after surgery. I reassure myself that we will completely heal the patients and send them home. Witnessing these patients recover and leave instills a unique sense of self-assurance in me (N14)."

Giving meticulous care: Nurses caring for children with CHD must be attentive and sensitive in their care and treatment. Nurses support patients both physiologically and psychologically throughout the process. The nurse emphasized the importance of ensuring that patients do not become tired during their care:

*"Devotion is essential for all patients, but children with CHD require extra attention because of their susceptibility to respiratory distress. Therefore, it is important to handle these cases with great care and caution, avoiding actions that could cause harm or fatigue. Even the slightest exertion can lead to respiratory distress in these children; therefore, we must be extremely vigilant. Our focus should always be on them, as even a moment of carelessness can lead to dangerous situations (N1)."*Some nurses highlighted the significance of nutrition for the speedy recovery of children with CHD. Nurses play a crucial role in preserving the nutritional well-being of children with CHD:

*"It is important to provide extra care and attention to children with this disease, as they require more support than healthy children or those with other health issues. Specifically, children with nutritional deficiencies require careful monitoring because developmental delays are common in these cases. We have to calculate their calorie needs, closely monitor their weight, and regularly check their blood values (N6)."*Nurses take a holistic approach to caring for children with CHD. They stated that having multiple skills is essential for providing care for these patients as follows:

"You need to have a thorough understanding of every detail. You must be extremely sensitive. We must consider the child as a whole. Pain, psychology, nutrition, and breathing are all included in this holistic approach. We are responsible for the patient's well-being from head to toe (N15)."

Theme 2: Interaction with the child

The theme of the study, titled "interaction with the child" focuses on nurses' communication with children and families. Effective communication increased the confidence of children with CHD and their families and improved their days in the hospital. On the other hand, despite the positive effects, some nurses avoided communicating with children with CHD and their families to protect themselves. The "interaction with the child" theme included three subthemes: development in the approach to pediatric patients, development in the approach to pediatric patients, strengthening communication with the family, and avoidance of communication.

Development in the approach to pediatric patients:

Caring for children with CHD has positively impacted nurses' social lives by enhancing their communication skills with children. The nurses' improved communication skills have made it easier to use in their personal lives, enabling them to communicate more effectively and healthily with their families and children. The nurses expressed their views as follows:

"Since working in this clinic, I have been connected better with children. I understand their needs, so they feel more comfortable around me. I appreciate their trust in me. This has also improved my relationship with my nieces and nephews (N13)."

Strengthening communication with the family: Nurses who care for children with CHD often form strong connections with families because of prolonged hospital stays and repeated surgeries. This enhanced communication allows families to develop trust, ask questions without hesitation, and receive education more effectively. However, the long-term interaction with these families can lead to nurses experiencing negative emotions, such as helplessness and fear that the families may experience, thus impacting the nurses' personal lives. The nurses expressed their views as follows:

"We have been together with moms and dads for a long time and have become a family." We also need to provide psychological support to the very worried families. It is challenging for them to care for a child, especially one with a difficult disease. Therefore, we need to provide them with great support. However, this can also be psychologically challenging for people (N2)."

"Families are understandably worried about this process. When they come here for the first time and do not know the environment, they naturally ask questions and make different demands. I empathize with them. If the families had been a little more understanding and patient, our working environment and psychology would have been better (N4)."

The nurse mentioned the positive aspects of strong communication with the family as follows:

"From a positive perspective, for example, I love talking to families. They consult with us on many issues, such as respiratory distress, drug use, and wound care. Training them on this subject will keep them updated in terms of knowledge. While it benefits families, it also strengthens us. In this respect, I also think having strong communication with family members is beneficial (N10)."

Avoidance of communication: Nurses play a crucial role in providing holistic care, support, and guidance to patients and their families. However, constant communication with patients and families can sometimes lead to negative effects, such as overempathizing with the feelings of families and carrying those emotions into their personal lives. As a result, some nurses may limit their communication with patients and families to protect themselves. The nurses expressed their views as follows:

"After some time, I began to feel psychologically unwell. I was constantly unhappy at home, and my thoughts always focused on the hospital. As a result, I started to limit my communication. I chat less with patient relatives to empathize less (N12)."

"I make an effort to keep my distance from the relatives of the patients. I get very sad when I form too strong a bond. I think it is healthier not to form strong emotional attachments with children to protect myself (N15)."

Theme 3: Psychosocial empowerment

The theme of this study, "Psycho social empowerment", examined the impact of caring for children with CHD on the values of nurses. Nurses were psychosocially empowered during professional experiences. It was the children they cared for who truly enriched their lives, teaching them about the value of life, the importance of hope, and the resilience to make the most of every situation. This theme comprised two subthemes: practicing patience and understanding the value of life.

Practicing patience: Nurses are crucial in supporting children and their families during long treatment processes, recurring surgeries, and unpredictable disease courses. A patient approach to the healing process of children and the concerns of families is an essential aspect of nurses' caregiving roles. While being patient contributes to the healing process in nurses' professional lives, it has also led them to better understand their social lives. The nurses expressed their views as follows:

"Children are the only group in the world who should not be sick, but unfortunately, they are. This realization has completely shifted my perspective of life. I have become more patient with my own children. Even if they do not well eat or are not successful in traditional terms, I no longer consider these things very important. What matters most to me is that they are healthy (N5)."

"I have learned to be more patient and not get angry with children over trivial things. My priorities have changed. For example, I realized there is no point in getting angry and pressing them just because they are not studying. I understand that they might have more important problems (N6)."

Understanding the value of life: While nurses observe the difficult struggles of children and their families, they also witness the fragility of life. These experiences change how nurses view their lives and lead them to appreciate the value of small moments and health more. Nurses state that, inspired by the stories of hope and resilience of patients and their families, they evaluate every moment of life in a more conscious and meaningful way. This awareness adds a deeper meaning to their personal and professional lives and reminds them that human life is. The nurses expressed their views as follows:

"I have children of my own, and I keep thinking about them. I am thankful that they are in good health and can pursue their desires, which has helped me understand the true meaning of life (N1)."

"One mother said: "Just listening to him breathe day after day is a miracle for us; one more day together is more precious than anything else." I always remember this sentence when I feel tired and overwhelmed by everyday problems (N9)."

Theme 4: Emergence of negative impacts

The theme “emergence of negative impacts” addresses the emotional, psychological, and physiological difficulties faced by nurses caring for children with CHD. Nurses are under intense stress and emotional burden because of the severe health conditions and uncertain prognoses of their patients. Prolonged hospitalizations and repeated surgeries increase the workload of nurses, leading to negative effects such as empathy fatigue and burnout syndrome. Nurses often experience feelings of hopelessness, anxiety, and helplessness during this process. This theme comprised four subthemes: Afraid of having a sick child, reflection of emotional burden in daily life, despair toward recovery, and physical disorders.

Afraid of having a sick child: Nurses caring for children with CHD often have concerns about their own maternal roles or their future dreams of becoming parents because of the challenging care processes. Witnessing the serious health problems experienced by children and the helplessness of their families deeply affected these nurses, leading them to worry about the health of their children. Many nurses have expressed fear that their children might be born with similar health problems in the future based on the cases they have encountered at work. Nurses expressed their views on this issue as follows:

“The most profound impact on me was experiencing fear; fear for my children, myself, and my relatives. My own child required intensive care. Going through that process felt like I was experiencing the same things as the children I care for and the same helplessness as their families. I was constantly worried that my child might need to be intubated or might experience a medical emergency (N11).”

“My husband also has a CHD.” That is why I feel much more fearful than other nurses. I wake up at night to check if my children are breathing. I am very afraid that they might also have heart disease. But if I didn’t know these things, if I didn’t work in such a clinic, I wouldn’t be affected at all (N13).”

“I was constantly worried about my child’s health during my pregnancy, to the point where I had multiple fetal echo scans done. Seeing other children only heightened my anxiety, and even the smallest signs of illness in my family caused me to panic (N14).”

Reflection of the emotional burden in daily life: The emotional burden of nurses caring for children with CHD extends beyond professional life and profoundly affects their personal lives. Nurses express that they are unable to disconnect mentally and emotionally from their responsibilities outside working hours. This constant state of anxiety about the well-being of their patients can disrupt the peace and serenity in the daily lives of nurses and their families. Simultaneously, this emotional burden limits nurses’ time to themselves, negatively affecting their psychological and physical health.

“We spend so much time with ill children here that I cannot stop thinking about them. When I go home, I feel unhappy (N3).”

“I constantly have ill children in my mind. Sometimes, in the evenings, I call to find out what has happened and the situation. I frequently tell my husband about my children at the hospital. My husband is also psychologically affected and very upset this time. This situation increases my emotional burden. I feel under pressure and exhausted at times (N4).”

“Sometimes, negative things from work follow me home. I have a headache, feel weighed down, and lack the energy to spend time with my children. I feel overwhelmed by my emotional burden (N6).”

Despair toward recovery: Nurses caring for children with CHD experience a deep sense of hopelessness and helplessness, especially for children who struggle to respond to treatment. Despite nurses’ best efforts, the chronic nature of the disease and occasional inadequacy of treatments can dampen their hopes for the children’s recovery. This sense of hopelessness affects their emotional well-being and affects their professional and personal lives. In addition, witnessing the worsening of the patient’s condition adds to the psychological burden experienced by nurses.

“There are children who receive treatment for a very long time and undergo repeated operations. While trying to instill hope in the families, we were despairing ourselves. This despair in the hospital affects my entire life; it changes my perspective. Perhaps psychological support can be given to employees (N10).”

“You are happy to see the children grow up, but now we know that, except for ASD and some VSDs, all children come again and again with a different diagnosis. It saddens me that the child you have bonded with for a long time repeatedly goes through the same processes and worries and becomes more aware as he grows up. I will try not to be hopeless, but I cannot help. Now, I look at many things in life more hopelessly (N14).”

Physical disorders: Nurses caring for children with CHD face significant physical challenges. They work long hours, lift heavy patients, and stand for extended periods, leading to various health problems, such as back, waist, and neck pain. The intense work pace and heavy care processes can also lead to fatigue and exhaustion, negatively impacting nurses’ overall quality of life. Therefore, nurses must receive physical support and protection while performing their duties.

“We lift and care for overweight children by ourselves, changing their diapers, and giving them baths. Our necks and backs are constantly in pain. Regardless of the child’s weight or whether they have COVID-19, we immediately took them to the intensive care unit without considering the

challenges of their weight, COVID-19, or physical discomfort. This puts patients at great risk of infection and physical strain (N1)."

"We experienced leg, back, and neck pain. Due to our heavy workload, we do not have time to rest. We are all here every day, working 12 hours a day. When we leave, we are very tired. Physically, we are all exhausted. If we had more nurses, we could relax physically (N7)."

"It is strictly forbidden to sleep during our night shifts at this hospital. Insomnia is very difficult for us, as we are constantly on duty and monitor patients in morning. This greatly tires the human brain and body. No matter how much I sleep, I cannot wake up rested when I leave the shift (N8)."

Theme 5: Overcoming challenges in professional life

The theme of the study "overcoming challenges in professional life" focuses on the significance of teamwork and institutional support. Nurses caring for children with CHD encounter numerous challenges in their professional lives, and they employ various strategies to overcome these challenges. Nurses emphasize the importance of unity and collaboration within their teams to manage the demands of intensive care, heavy workloads, and emotional stress. Sharing knowledge and experiences with colleagues is crucial for overcoming these difficulties. This theme comprised two sub-themes: team collaboration and institutional support.

Team collaboration: Nurses caring for children with CHD must emphasize the critical role of team collaboration in overcoming care-related challenges. They stressed that effective communication and teamwork among staff members speeded up and improved patient care. Nurses highlight the significance of collaborative teamwork, particularly in complex cases, and underscore that leveraging the knowledge and expertise of various disciplines enhances patient care. They also noted that open and regular communication and workload sharing reduced emotional and physical burnout.

"Children's needs must be comprehensively addressed." Physiological needs such as nutrition and physical activity are as important as medical treatment and surgery. We rely on the expertise of physiotherapists and dieticians for support. When the team collaborates effectively, the workload becomes more manageable, leading to better patient care and greater satisfaction for us (N2)."

"Caring for a child with CHD requires teamwork and effort." Nurses, physicians, dieticians, and staff all play crucial roles. Collaboration is essential for the best patient care. When we support each other, it eases our psychological burden. Working together as a team to care for a sick child significantly enhances professional satisfaction (N5)."

Institutional support: Nurses caring for children with CHD stressed the importance of institutional support in assisting

children in coping with the challenges they encounter in their professional lives. They emphasized that the support received from healthcare institutions is crucial in preventing physical, emotional, and professional burnout. Specifically, managers' support in addressing issues such as understaffing, long hours and heavy workloads is instrumental in strengthening nurses' professional resilience.

"As members of a profession that significantly impacts our lives, we require support from our managers. Considering how much time and effort we dedicate to our profession, financial support is especially important to us. We also seek satisfaction in terms of financial compensation. At the same time, shorter working hours and increased vacation time serve as motivational incentives and help mitigate the negative impacts on our lives (N3)."

"Our working conditions are challenging, and as a result, we have certain expectations from our managers. Meeting staff needs, showing more understanding, and meeting financial expectations are crucial for meeting our basic needs. Reducing the number of patients receiving care can also enhance the quality of care (N11)."

Nurses emphasized the importance of providing psychological support:

"The sense of hopelessness we experience because of chronic illness and repeated hospitalizations also affects our own lives. Therefore, hospital management can provide regular psychological support (N6)."

"We have patients who we follow for long periods, and sometimes, they deteriorate or pass away. This can be very difficult for some nurses, leading to psychological distress. While we try to give them time off, our staffing levels are low, and they often must continue to work. Perhaps we could provide psychological support to help our nurses during such challenging times (N12)."

Discussion

Caring for children with CHD is a challenging and arduous task. The treatment involves a multitude of issues, including complexity, lifelong management, challenges related to growth and development, exercise tolerance, nutrition, psychosocial well-being, transition of care, and the risk of complications, such as heart failure (1,20). This requires specialized comprehensive care approaches that are distinct from those for other chronic diseases. Parents of children with CHD are significantly more likely to experience psychological problems such as anxiety, depression, caregiver burden, and poor quality of life when their caregiving needs are not met by healthcare professionals (21-23). Therefore, as members of a multidisciplinary care team, nurses play an important role in addressing the care needs of patients and families (20). A previous study demonstrated that higher nursing skills and experience

were significantly associated with fewer complications after pediatric cardiac operations (11). The impact of nursing care on children with CHD and their families has been extensively studied (21,24,25). However, there is a lack of research on how caring for children affects nurses' lives. Therefore, taking into account the experiences from all aspects of nurses' lives can offer a more comprehensive understanding of a person-centered approach to care. This approach can also serve as a foundation for integrated health services that emphasize the unique needs and preferences of these nurses, guiding the development of quality care. Working in pediatric cardiology clinics can be challenging and stressful for healthcare professionals (6). Although most previous research has predominantly focused on the negative effects of caring for this patient population on healthcare providers (6,9,10,26), our study is the first to explore and establish a correlation between both the positive and negative impacts of caring for children with CHD on nurses' lives. The impact of caring for children with CHD on nurses was analyzed. The results showed that caring for children with CHD had both positive and negative effects on nurses' lives, whether emotional, psychosocial, or professional. Moreover, nurses encountered physical challenges that required institutional and psychosocial support.

Our results revealed that meticulous care for children with CHD empowered nurses' professional and personal lives in terms of their self-confidence, knowledge, and skills. Studies have examined the impact of working in pediatric units that require intensive nursing care on nurses' professional lives and found that it increases job satisfaction and skills (26,27). Nurses in the present study also highlighted that nurses working in pediatric cardiology units should continuously enhance their skills and focus on providing specialized care for children. Pediatric cardiology nurses need to have a clear understanding of CHD, including the cardiac structure, pathophysiology, and care demands of these patients (7). This understanding will enable clinicians to provide better and more holistic care to pediatric cardiology patients and their families. In addition to these findings, our study revealed that working in pediatric cardiology units provided the opportunity to consult children in nurses' social environments, such as their friends and relatives. Although this phenomenon has not been widely documented in prior studies (9,10), it underscores the broader societal impact of pediatric cardiology nurses' specialized skills. This finding may reflect the nurses' strong sense of responsibility and commitment to extend their professional knowledge beyond the workplace, a perspective that warrants further exploration in future research.

In this study, "interaction with the child" emerged as an important aspect of nurses' experiences caring for children with CHD. Nurses in the study frequently highlighted the strong communication they developed with children under their care. This finding is consistent with the existing literature, which emphasizes the critical role of pediatric nurses in providing continuous support to patients and

managing their emotional processes (28,29). Our findings revealed that interactions with these patients, while emotionally intense, form a crucial part of the caregiving experience and deeply influence nurses, both professionally and personally. Similarly, a previous study demonstrated that enhancing pediatric nurses' communication with families and patients positively impacted the care provided to the children and the nurses' communication with their children (30). Nurses fulfill their professional responsibilities while also providing emotional support and connecting with the children they care for on a personal level (31). However, emotional devotion also poses challenges (6). Nurses described the difficulty of balancing caring deeply for the child and maintaining professional detachment to avoid emotional burnout. Nurses also noted that they occasionally limited their communication with children to maintain emotional balance and protect themselves.

Caring for children with CHD also contributes significantly to nurses' personal development. Nurses frequently noted that caring for these vulnerable children required them to cultivate greater patience in their clinical tasks and interactions with patients and families. This heightened sense of patience stemmed from the long-term nature of CHD treatment, which often involves extended periods of hospitalization and complex care regimens. This finding is consistent with the existing literature suggesting that patience is a crucial skill for nurses in critical care settings, where care's emotional and physical demands are particularly high (32,33). This personal growth enhanced their professional capabilities and improved their interactions with colleagues, family members, and children. The ability to remain patient in adversity reflects these nurses' deeper emotional resilience, underscoring the positive psychosocial impact of caring for critically ill children. Nurses frequently described how witnessing the resilience of these young patients, many of whom face life-threatening conditions, led them to develop a deeper appreciation for life's fragility and significance. Nurses noted that their experiences caring for CHD patients had a lasting effect on their values, often prompting them to re-evaluate their priorities and relationships. This shift in perspective is consistent with findings from other studies, which showed that healthcare professionals working in critical care environments often experience a heightened awareness of the value of life and the importance of making the most of everyday moments (27,28). Similarly, a study examining nurses' experiences in intensive care units emphasized that nurses caring for children with complex health problems focused more on the value of life (34). This experience not only reinforced the value of life but also motivated nurses to provide the highest quality of care, knowing that their efforts could make a significant difference in the lives of these children (35). Additionally, the emotional insight gained from these experiences often extended beyond the workplace, with nurses reporting that they became more empathetic and mindful in their personal lives, recognizing the importance of cherishing their loved ones.

The results of our study are crucial for understanding the adverse effects of caring for children with CHD among nurses. This is consistent with previous studies that have observed that nurses are especially susceptible to negative mental health effects, such as increased anxiety levels and emotional fatigue when working with children (36,37). Moreover, previous studies have shown that pediatric nurses working in excessively stressful conditions are more susceptible to physical exhaustion and health problems (38,39). Furthermore, our results resonate with Tito et al. (10), who identified symptoms of tension, irritability, and anxiety as common among pediatric cardiology nurses. This reflects broader findings in the literature, which indicate that healthcare workers in high-stress environments often struggle with emotional burnout and difficulty establishing a work-life balance (40,41). These findings emphasize the need for mental health protection measures, such as stress management training, peer support programs, and access to professional psychological services. Therefore, health professionals should be adequately supported through various individual and group psychological interventions to help them feel productive and valued and improve their social and motivational attitudes (37,39).

Nurses often experience deep emotional impacts because of their work with CHD. Many nurses expressed heightened anxiety about their children's health or the possibility of having a child with a serious condition in the future. The constant exposure to severe cases of CHD and witnessing the suffering and struggles of families deeply affected nurses' perceptions of parenthood and their concerns for their children's well-being. Similarly, studies have shown that healthcare professionals frequently develop heightened fears and anxieties related to the health of their loved ones when exposed to critical illness in their professional environment (42,43). A unique finding of our study was the impact of caring for children with CHD on nurses' perspectives of parenthood, particularly regarding raising concerns about their children's well-being. Although similar emotional effects have been documented in other groups, the specific influence of parenting perceptions within this population has been less frequently explored. Nurses frequently expressed feelings of hopelessness when patients failed to respond to treatments or experienced chronic relapses despite ongoing efforts. The emotional strain of managing long-term, complex cases, coupled with the uncertainty of recovery outcomes, left many nurses feeling disheartened and emotionally drained. This sense of despair is a well-documented phenomenon in healthcare settings where professionals work with critically ill patients, often leading to compassion fatigue and emotional exhaustion (44,45).

Nurses caring for children with CHD overcome many challenges in their professional lives. Team cooperation and institutional support play an important role in coping

with such challenges (46). Nurses emphasized that working closely with physicians, dietitians, physiotherapists, and other healthcare professionals was essential for delivering comprehensive care to children with CHD. The interdisciplinary approach helped to share the workload and improved patient outcomes by ensuring that all aspects of the child's care were addressed. This finding aligns with those of previous studies, demonstrating that teamwork in healthcare settings leads to better patient care and reduces the emotional and physical strain on individual nurses (45,46). By fostering a culture of open communication and mutual support among team members, nurses could feel more confident in their professional roles, contributing to job satisfaction and resilience in the face of challenges (47-49). The findings of the present study align with those of Bagnasco et al. (9), who reported higher burnout rates among pediatric cardiology nurses in countries with limited staffing and resource allocation compared to those with robust support systems. Moreover, nurses noted that adequate staffing levels, access to mental health resources, and supportive management were vital in preventing burnout and maintaining their ability to provide high-quality care. Nurses particularly valued managers who were responsive to their concerns, whether by addressing staffing shortages or facilitating opportunities for professional development. A systematic review emphasized that organizational support, including mental health services and appropriate workload, is crucial for reducing burnout and improving nurse retention in high-stress environments (50). This parallel underscores the critical impact of institutional and systemic factors on nurses' well-being.

This study underscores the dual impact of caring for children with CHD on nurses' lives. While it leads to professional growth and psychosocial empowerment, it also imposes significant emotional, psychological, and physical demands. The findings point to the need for healthcare institutions to provide comprehensive support, including adequate staffing, psychological services, and mechanisms for emotional relief, to ensure the well-being of nurses and maintain the quality of care they provide.

Study Limitations

The current study is the first to determine the impact of caring for children with CHD on nurses' lives. In this context, this study's findings may fill in the information gap in the literature by identifying these effects to bolster the healthcare system and patient care approaches. Adherence to the COREQ checklist is a significant strength of this study, contributing to its methodological rigor and quality of reporting. However, this study is limited to a single hospital, and future research should explore nurses' experiences in different settings to enhance the generalizability of the findings. Additionally, the current study focused only on nurses, and future studies could include other healthcare professionals to gain a more comprehensive understanding of the impact of caring for children with CHD.

Implications of practice

The findings of this study highlight the critical need for institutional support to address the emotional, psychological, and physical challenges experienced by nurses caring for children with CHD. Healthcare institutions should implement mental health services, team-based support systems, and professional development opportunities. Integrating mental health services and peer support groups can offer nurses a safe space to process their experiences, thereby providing psychological support and fostering teamwork that can mitigate the emotional burden and reduce burnout among nurses. Furthermore, by ensuring adequate staffing, fair compensation and access to ongoing education, institutions can create a sustainable work environment, enhance nurses' resilience and job satisfaction and improve patient care quality. These changes are necessary to create a sustainable work environment where pediatric nurses can thrive professionally and personally. Developing specialized training programs, such as covering advanced topics like managing complex cardiac conditions, delivering family-centered care, and addressing the psychosocial needs of both patients and families, and the objectives focusing on enhancing clinical competencies, improving communication skills, and fostering resilience through stress management techniques for nurses working with children with CHD is crucial not only to improve care outcomes for children with CHD but also to support the professional and personal growth of pediatric nurses, aligning clinical practices with broader policy development goals.

Conclusion

Caring for children with CHD has both positive and negative impacts on nurses' lives, affecting them emotionally, professionally, and personally. While nurses gain significant professional knowledge, skills, and psychosocial resilience, they experience compassion fatigue, emotional exhaustion, and physical strain. The strong emotional bonds formed between patients and families can lead to both fulfillment and emotional burdens. Institutional support, mental health services, and team collaboration are vital for managing these challenges. This study emphasizes the importance of creating supportive and well-structured work environments to ensure nurses' well-being and the continued provision of high-quality care for children with CHD.

Ethics

Ethics Committee Approval: This study was approved by the Baškent University Medicine and Health Sciences Research Board (date: 06.02.2024, no: KA24/62) and was approved by Baškent University Hospital Nursing Directorate Services. This study was conducted using the Principles of the Declaration of Helsinki.

Informed Consent: The nurses were informed about the purpose and methodology of the study, verbal and written consent was obtained.

Footnotes

Author Contributions: Conception – A.A., İ.E.K., A.G.; Design – A.A., İ.E.K., A.G.; Data Collection and/or Processing – A.A., İ.E.K., A.G.; Analysis and/or Interpretation – A.A., İ.E.K., A.G.; Literature Review – A.A., İ.E.K., A.G.; Writing – A.A., İ.E.K., A.G.

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