

# Struggling and Overcoming Daily Life Barriers Among Children With Congenital Heart Disease and Their Parents in the West Bank, Palestine

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Kawther Elissa, RN, MSN<sup>1,2</sup>,  
Carina Sparud-Lundin, RN, PhD<sup>1</sup>,  
Åsa B. Axelsson, RN, PhD<sup>1,3</sup>,  
Salam Khatib, RN, PhD<sup>2</sup>,  
and Ewa-Lena Bratt, RN, PhD<sup>1,4</sup>

## Abstract

Advances in early diagnosis, treatment, and postoperative care have resulted in increased survival rates among children with congenital heart disease (CHD). Research focus has shifted from survival to long-term follow-up, well-being, daily life experiences, and psychosocial consequences. This study explored the everyday experiences of children with CHD and of their parents living in the Palestinian West Bank. Interviews with nine children aged 8 to 18 years with CHD and nine parents were analyzed using content

<sup>1</sup>Institute of Health and Care Sciences, Sahlgrenska Academy, University of Gothenburg, Gothenburg, Sweden

<sup>2</sup>Al-Quds University, Jerusalem, Palestine

<sup>3</sup>Sahlgrenska University Hospital, Gothenburg, Sweden

<sup>4</sup>Department of Pediatric Cardiology, Queen Silvia Children's Hospital, Gothenburg, Sweden

## Corresponding Author:

Kawther Elissa, Lecturer, Department of Nursing, Faculty of Health Professions, Al-Quds University, Abu Dies Campus, P.O. Box. 89, Jerusalem, Palestine. Institute of Health and Care Sciences, Sahlgrenska Academy, University of Gothenburg, Sweden.

Email: kawtheralayasa@gmail.com

analysis. The overall theme that emerged was facing and managing challenges, consisting of four themes: sociocultural burden and finding comfort, physical and external limitations, self-perception and concerns about not standing out, and limitations in access to health care due to the political situation. To provide optimum care for children with CHD and their parents, health care providers and policy makers must understand the negative consequences associated with sociocultural conditions and beliefs about chronic illness.

**Keywords**

adolescent, child, congenital heart disease, parents, Palestinian, qualitative

The incidence at birth of congenital heart disease (CHD), internationally as well as in Palestine is 9.1 per 1,000 live births (van der Linde et al., 2011; Zaqout, Aslem, Oweida, & De Wolf, 2014). In the Palestinian territories, approximately 257 newborns were diagnosed with CHD in 2012 (World Health Organization [WHO], 2014a). The improvement in diagnosis and treatment of CHD has resulted in an increased survival rate, and today, more than 95% reach adulthood (Mandalenakis et al., 2017; Moons, Bovijn, Budts, Belmans, & Gewillig, 2010). Therefore, focus has shifted from survival to long-term follow up, well-being, daily life experiences, and psychosocial consequences.

Caring for a child with CHD is a stressful experience for families with an impact on family life at various levels because of the increased burden and responsibilities imposed on these families (Almesned, Al-Akhfash, & Al Mesned, 2013; Wei, Roscigno, Hanson, & Swanson, 2015; Wray et al., 2018; Wray & Maynard, 2006). The majority of previous studies addressing psychosocial aspects and impact of CHD on the daily life of children and family have been conducted in Western countries (Cornett & Simms, 2014; Knowles et al., 2016; Rassart, Luyckx, Goossens, Apers, & Moons, 2014; Shearer, Rempel, Norris, & Magill-Evans, 2013; Sira, Desai, Sullivan, & Hannon, 2014). However, it is important to emphasize that the sociocultural/political context, family dynamics, religion, and health care systems vary across societies, and it is likely that these factors have an impact on well-being and psychosocial issues.

In Arab Muslim societies including Palestine, family is considered the basic social unit and tends to be traditional and patriarchal (Haj-Yahia, 2005). Men are regarded the head of the household, responsible for family finances and decision making, whereas the women's role revolves around getting married, homemaking, nurturing, and disciplining children (Aroian, Katz, & Kulwicki, 2006). In addition, the consequences of the Israeli occupation play a significant role, causing major challenges because of the separation wall

and checkpoints, which split families and restrict mobility (closure; Batniji et al., 2009; Keelan, 2016; Spellings, 2014). The political and economic situation further compromises health, the organization of the health care system, and quality of health services (Giacaman et al., 2009). When critical medical interventions or services are unavailable in the West Bank, Palestine, the Ministry of Health (MOH) refers patients to Israel, Jordan, Egypt, and Palestinian hospitals in East Jerusalem. Furthermore, Palestinian patients and their families have to apply for permits from Israeli authorities to enter Jerusalem or Israel for health care, even with a referral (Keelan, 2016). Children can be denied access to care if no one from the family receives permission to accompany them. About one fifth of patients who applied for health care access permit to hospitals in Jerusalem or Israel in 2016 were denied it or the permit was delayed (WHO, 2016).

Exploring everyday life experiences increases knowledge and provides insight for health care providers and policy makers to achieve a better understanding of the challenges and needs of living and coping with CHD in the occupied territories; the findings are also applicable to those with other chronic conditions living under similar circumstances. Therefore, the aim of this study was to explore the experience of daily life in children with CHD and their parents in the Palestinian West Bank.

## **Method**

### ***Design***

An inductive qualitative descriptive design with face-to-face interviews was used.

### ***Setting***

This study took place in West Bank, Palestine. West Bank has an estimated population of 3.01 million (Palestinian Central Bureau of Statistics [PCBS], 2017) and a land area of 5,640 km<sup>2</sup> (Global Business and Investment Center, 2017). Population density (inhabitants/km<sup>2</sup>) is 532 in the West Bank, which is considered as a high population density (PCBS, 2017). Nearly 73% of the population lives in urban areas, 17% in rural areas, and 9% in refugee camps (PCBS, 2012). Palestine is a part of the Middle East region and has been occupied by Israel since 1948. However, in accordance with the Oslo agreement, the Palestinian Authority (PA) was established in the year 1994. The Palestinian community is a relatively homogeneous mixture of Muslims (94%), Christians (6%), and a small Jewish minority (Giacaman et al., 2009).

## *Participants*

As part of the recruitment process, letters with study information and consent forms were sent to a charitable hospital in East Jerusalem, which covers cities in the south, north, and middle region of the West Bank, asking for their agreement to recruit participants. Upon receiving the agreement of the nurse-in charge at the hospital, all potential participants were identified. Those who met the eligibility criteria and were willing to describe their everyday lives were given the study information letter and consent form. In addition, the participants' contact details were provided by the nurses and the secretary of the department of pediatric cardiac surgery and congenital heart defects at the hospital. Inclusion criteria were children aged 8 to 18 years with CHD and their parents. A purposeful sampling procedure was used to choose participants, which aimed to reflect the diversity of the population. Nine children with CHD and nine parents were selected from various locations in the West Bank. To achieve a good sampling variance, the participants were selected from urban, rural, and camp settings, as well as from different age groups and both sexes and having various heart conditions (see Table 1).

## *Data Collection*

Data were collected via face-to-face interviews with nine children with CHD and either the mother or the father of each child (nine children, five mothers, four fathers). The interviews were conducted by the first author (KE) and held in the participants' homes. The children and parents were interviewed individually, to give them the opportunity to talk openly about their experiences without restrictions. An interview guide was used and the following main questions were posed to the children: "Can you describe your CHD and how do you think it affects your daily life?" "What is a typical day like for you right now?" and "On a typical day, what sorts of things do you do that might set you apart from your friends?"

For the parents, the following main questions were posed: "Can you describe your child's CHD and how you think it affects your child's daily life?" "Can you tell me about how you think your life and the family's life are affected by the fact that your child has a CHD?" "How has the diagnosis influenced your child (emotionally, physically, and socially)?"

All interviews were conducted in Arabic, which was the native language of the participants, the main author (KE), and the fourth author (SK). The interviews were performed between March and December 2015; they lasted between 30 and 60 min and were audio recorded with the permission of the participants. The first author transcribed all the interviews and translated them to English. To avoid potential translation bias, all transcripts were reviewed by a bilingual health professional.

**Table 1.** Sociodemographic Data of Children With CHD and Parents and the Type of Heart Disease.

Variable	Mothers (n = 5)	Fathers (n = 4)	Children male (n = 5) female (n = 4)
<b>Educational level of parents</b>			
Illiterate	1		
Primary school	1		
High school	3	3	
Diploma		1	
<b>Occupation</b>			
Housewife	5		
Worker		3	
Employee		1	
<b>Residency<sup>a</sup></b>			
Urban (>4,000 residents)	2	2	4
Rural (<4,000 residents)	2	1	3
Camp <sup>a</sup>	1	1	2
<b>Family situation</b>			
Living with two parents	5	4	9
<b>Primary CHD diagnosis</b>			
Pulmonary atresia			1
Tetralogy of Fallot			1
Large VSD with coarctation of the aorta			1
Pulmonic valve stenosis and mild tricuspid regurgitation			1
Sever aortic stenosis and aortic valve stenosis			1
Large patent ductus arteriosus			1
Transposition of great arteries			1
VSD			2

Note. CHD = congenital heart disease; VSD = ventricular septal defect.

<sup>a</sup>Camp: It refers to any locality referred to as a refugee camp and administered by the United Nations Refugees and Work Agency in the Near East.

**Ethical Considerations**

Ethical approval for this study was obtained from the ethical committee at Al-Quds University. The parents signed a consent form, and the children were also asked whether they agreed prior to their inclusion in the study. The participants were reassured of the confidentiality and anonymity of their participation. The study was conducted according to the Declaration of Helsinki (World Medical Association, 2013).

## Data Analysis

Content analysis was used to analyze data, in accordance with the steps outlined by Graneheim and Lundman (2004). The transcripts were reviewed several times to gain a comprehensive sense of the whole. The interviews were divided into meaning units of words, sentences, or paragraphs. These meaning units were then condensed into shorter statements, abstracted, and labeled with a code. Finally, through reflective and collaborative discussions among the authors about the accuracy of interpretations throughout the abstraction process, the codes were grouped into subthemes and themes (see Table 2 for an example of the analysis process). To enhance conformability and trustworthiness, and to decrease personal bias in the study, the transcribed interviews and coding system were reviewed by the authors until agreement was reached.

**Table 2.** Examples from the Analytical Process.

Meaning unit	Condensed	Code	Subtheme	Theme
It is God's will so I have to accept it as what is from God is good, thank God for everything. What God wants it should be. And I am satisfied with the wisdom of God.	Feeling thankful, satisfied with God's will, and relying on God	Thankful and relying on God	The impact of religion and fatality as a facilitator in managing the disease	Sociocultural burden and finding comfort
He was negatively affected by how friends deal with him as they prevented him from playing because they thought he is weak and sick. His nervousness might be due to feelings of insufficiency as he couldn't participate in the activities that he likes such as play.	Friends prevented him from playing as they thought he is weak and sick to play	Labeling and devaluing	Stereotyping and feeling of being devalued	

## Findings

Facing and managing challenges was the overall theme and represented the struggle to overcome barriers and isolation that children and their parents experienced in their daily life. The overall theme consisted of four themes and nine subthemes (see Table 3). The four themes were sociocultural burden and finding comfort, physical and external limitations, self-perception and

**Table 3.** Overall Theme, Themes, and Subthemes.

Overall theme			
Facing and managing challenges			
Themes			
Sociocultural burden and finding comfort	Physical and external limitations	Self-perception and concerns about not standing out	Limitations in access to health care due to the political situation
Subthemes			
Stereotyping and feelings of being devalued	Physical symptoms limiting daily life	Body image concerns	Barriers in access to health care
The impact of religion and fatality as a facilitator in managing the disease	Restrictions imposed by the societal environment	Worries about marriage opportunities	Social isolation when hospitalized
	Financial difficulties		

concerns about not standing out, and limitation in access to health care due to the political situation. Daily life was influenced negatively by societal stereotyping, the political struggle, and children’s perceptions of their illness. Although, this affected every aspect of their lives, they explained that their reliance on God facilitated their acceptance of their fate and lives.

***Sociocultural Burden and Finding Comfort***

Societal and cultural aspects influenced daily life and affected decisions regarding health and social well-being of children with CHD and their parents. In addition, this theme represented negative experiences, such as stereotyping and feelings of being devalued, as well as positive experiences caused by the participants’ religious beliefs, which seemed to be the key facilitator that helped them to accept and manage life.

*Stereotyping and feelings of being devalued.* This subtheme refers to the negative attitudes and reactions of the close-knit society toward children with CHD and their parents. This subtheme represents one of the main difficulties experienced by children and their parents, and was experienced as beyond

their ability to overcome. This was also viewed as a major barrier that they faced in their daily interactions. They believed that the disease contributed to others perceiving them in a negative and judgmental way, which led to the feeling of being stigmatized. Children with CHD felt that people underestimated their abilities by perceiving them as weak, inferior, and less valuable. Feelings of being devalued influenced the children's interaction with peers and resulted in social isolation, as a 17-year-old girl said, "Classmates avoid discussion or clashes with me because they consider me sick and weak. They fear they will be blamed if something happens to me."

He was negatively affected by how friends dealt with him as they prevented him from playing as they thought he is weak and sick. His nervousness might be due to feelings of insufficiency as he couldn't participate in the activities that he likes such as play. (Mother of a 16-year-old boy)

Negative reactions created a sense of fear and uncertainty about future discrimination and stigma in relation to social standing, career, and marriage. Therefore, sometimes parents and family members preferred to hide the disease as a means of protecting the family reputation and not jeopardizing their daughter's future marriage. Furthermore, some children expressed their fears that others could gossip about them and perhaps perceive them as contagious, as a 16-year-old girl said, "I do not tell my friends about my disease. I am afraid that they may stay away from me the same as my relatives did. Maybe they think it is contagious."

I'm afraid about her future, people will not understand her condition, and they will underestimate her abilities due to her CHD. We are still afraid that companies will not hire her because of her illness; she will create new burdens for them. (Mother of an 11-year-old girl)

Some children and parents believed that telling people about the disease could result in negative consequences for their social standing. Young male adolescents who decided to talk about their CHD had faced experiences such as their girlfriend ending the relationship directly when the CHD was revealed. The social consequences of the disease spread to affect relationships between mothers and in-laws, as the latter put pressure on fathers to take a second wife to have healthy children, as a mother of a 16-year-old stated, "Relatives around me impact our private life and encourage my husband to marry again as he has the right to have healthy children as others do."

Some parents were aware of potential negative consequences of stigma on their children's future career. Therefore, they had found constructive ways to



deal with it through encouraging and emphasizing the importance of education for their children to empower them to be independent in the future, as a mother of an 11-year-old girl said, “We take care of her education to be economically independence. Good education helps her to have a good job as CHD limits physical activities.”

*The impact of religion and fatality as a facilitator in managing the disease.* This subtheme represented the effect of faith, religious beliefs, and fate on children with CHD and their parents in overcoming the struggles and challenges they faced in their daily life. Fatality is referred to the belief that all events are part of God’s will. All children and their parents believed that everything in the universe is controlled by God’s will and everything that is related to health or illness is a result of divine fate. Some parents believed that illness is a test from God, which they should accept and not a punishment for sins, as others claimed. They trusted God and relied on him instead of complaining and objecting about what God had chosen for them. A sense of fatality about illness and reliance on God was adopted by the children and their parents for managing the disease and controlling community pressure, as a father of a 16-year-old girl said, “We say thanks to God, what comes from Him is a blessing; good or bad. A person should persist and should tolerate God’s will and should be patient regardless what problems that person will get.”

It’s God’s will so I have to accept it as what is from God is good, thank God for everything. What God wants it should be and thanks God for everything. And I am satisfied with the wisdom of God. (Boy, 15 years old)

Some participants also believed that God is capable of curing illness, so they regularly practiced religious activities such as reading from the Holy Qur’an and praying at a mosque as ways of coping and seeking help and hope.

### *Physical and External Limitations*

This theme consists of three subthemes: physical symptoms limiting daily life, restrictions imposed by the societal environment, and financial difficulties. Children with CHD and their parents faced barriers related to physical and external limitations and they could succeed in managing these challenges, either by themselves and/or by support of their parents. These limitations had a negative influence on children’s and parents’ daily life and intensified children’s suffering and feelings of isolation.

*Physical symptoms limiting daily life.* This subtheme is related to the consequences of physical symptoms such as breathlessness, chest pain, fainting, fast heart rate, and exhaustion on physical activities of children with CHD. Children and their parents reported different experiences with physical limitations. Due to physical symptoms, some children were unable to participate in strenuous activities such as running, whereas some experienced difficulty walking and using stairs.

I have a problem with the stairs from my home to the main road down or upstairs, I have to take it step by step. Every five steps I have to take a rest for three minutes at least, because of shortness of breath and chest pain. (Girl, 11 years old)

The discrepancy between the children's desire to play and engage in physical and recreational activities, and their inability to do so, affected how they perceived themselves. It had a negative impact because they struggled with their physical limitations. They wanted to take part in physical and social activities but they were unable to do so because of their physical symptoms, which limited their daily life activities and left them feeling that they failed to achieve what other children can do, as a 10-year-old girl said, "I feel weak and cry as my cousins run and walk without getting tired."

Peers keep playing and don't get tired like I do. Sometimes I just play for 10 minutes and get tired. They get tired but they continue after that, not like me. I keep thinking about life. Like why I am like this, why I am not like them? I wish I could be like other boys without a disease. (Boy, 15.5 years old)

Some children also felt isolated from peers when they could not participate in physical and fun activities or when they could not keep up with friends. Physical limitations affected emotional well-being of these children and intensified their negative feelings and fears about the future.

I have a feeling of sadness and bitterness as peers always play and run and have fun while I always feel tired quickly. Sometimes I play and feel tired but never tell my friend that I am tired because I fear they will stop playing with me so I will be isolated and no one will be friends with me. (Boy, 13 years old)

To avoid isolation, the children developed new strategies to manage physical limitations and to engage in physical activities. Taking a rest and withdrawing from a game was a strategy for most children to overcome physical symptoms associated with physical activities, as a 16-year-old boy said, "I can't play for as long as others, so I take a rest and continue the activity after feeling better."

The impact of physical limitations extended beyond children's positive interactions with their peers to include peers bullying them. Peers could be unsupportive by showing lack of understanding and empathy, as a 13-year-old boy said, "Sometimes peers prevent me from returning back to play when I leave and start to shout at me as I can't play regularly and constantly like them."

*Restrictions imposed by the societal environment.* This subtheme refers to physical and recreational activities that are restricted by others, such as parents, doctors, and teachers on children with CHD. Most of these restrictions focused on physical activities, sport, and recreational activities. In general, most parents prevented their children from participating in highly energetic activities such as running, and they informed the school to not push their children too hard during sport and physical activity to avoid exhausting them. Therefore, participation in school gymnastics was a matter of concern. They participated but stopped when they got tired. Some were completely excluded from gym class in response to the parents' request or because the school staff feared complications associated with physical activity, as a mother of an 11-year-old girl said, "The doctor emphasized restricting sport and her father informed the sports teacher about this and her CHD."

For others, the physical education teacher prevented them from finishing a physical activity even before they got tired or had physical symptoms. Restriction of physical and recreational activities created a sense of loneliness and was bothersome for the children because of the insensitivity of some teachers, who exposed the child's restrictions in front of other classmates, as a 16-year-old boy said, "Last week the sports teacher asked me to sit although I was not tired. He did this in front of the whole class so this is annoying to me."

Parental overprotectiveness was one of the main reasons for imposing restrictions on children, as the parents feared that there would be complications associated with physical activities. Some children described how their parents, especially their mothers, even prevented them from going out to be with friends, to keep the child under their watchful eye. The children perceived these restrictions as unnecessary, and some of them believed that they were based on incomplete knowledge and underestimation of their abilities and a kind of domination, which inflicted more tension and anger.

I think sometimes my parents exaggerate their fears and give me a lot of recommendations and advice in what to do and what not to do. I am not a child and I can take care of myself. They should trust me more because this sometimes annoys me as they want to control my life and want to know everything I do.  
(Boy, 16 years old)

To manage challenges associated with physical restriction, some children rejected and rebelled against advice and restrictions imposed on their physical activities and engaged in strenuous risky activities to prove to their peers that they were capable and strong, and to avoid social stigma and rejection. Others accepted their limitations by choosing alternative activities such as singing and painting to compensate for their physical limitations and restrictions.

He jumps from the neighbor's roof to prove that his friends are not stronger than him. He told me he is not a child and doesn't have a dangerous disease to restrict his physical activities. He likes to play games that are forbidden like football and boxing. (Mother of a 16-year-old boy)

**Financial difficulties.** Most of the parents reported experiencing financial difficulties due to high treatment costs. To overcome financial challenges, some parents were forced to seek financial help from relatives and friends to deal with their financial restraints and to afford treatment. A mother of a 16-year-old said, "Sometimes I couldn't provide money to pay for follow-up appointments, so I deducted from my family expenses to save up the needed money."

Although all the parents had medical insurance, the unavailability of some medications in the governmental and United Nations Relief and Works Agency for Palestine Refugees in the Near East (UNRWA) clinics in the West Bank forced these parents to buy medications themselves. Furthermore, the long wait for service in the governmental clinics forced them to pay for services provided in private clinics.

At the government hospital, they don't take into consideration the child's need for regular follow-up, so this may affect my son's condition as we may visit a private doctor twice at our own expense while waiting for an appointment at the government clinic. (Mother of a 16-year-old boy)

### ***Self-Perception and Concerns About Not Standing Out***

This theme represents both the barriers that children with CHD and their parents faced and their attempt to manage challenges they faced in their daily life. Various concerns and worries led to constant inner conflict about the children's ability to not stand out in their social life such as body image concerns and worries about marriage opportunities. The process of being concerned not to stand out was reported by most children to be problematic, as it intensified emotional pain, suffering, and dissatisfaction, which affected all aspects of their lives. Although some children succeeded in dealing with the embarrassment associated with their physical appearance, they still felt overwhelmed when thinking about the future and the risk of not being like everyone else.

*Body image concerns.* This subtheme refers to how children with CHD perceived their body and physical capacity. The CHD was associated with negative perception of their physical appearance and diminished self-worth. Body image concerns were one of the difficult experiences reported by children and their parents. Children reported their experiences about how their CHD influenced their self-image with regard to scars and short stature. Some children, especially girls, perceived their body as ugly because of their postsurgical scars, as a 10-year-old girl said, "It hurts me that I have this ugly scar which makes me ugly." Girls were preoccupied with how to hide their surgical scars by wearing a turtleneck or V-neck as a way to avoid being the center of attention and to avoid social stigma and its implications. These girls felt ashamed of their appearance and less attractive, which affected their self-esteem and self-confidence, as a mother of an 11-year-old girl said, "She always asks about the scar in her chest and wonders if it will disappear or not, as it has distorted her appearance."

Boys avoided taking their shirts off when they went swimming, to avoid drawing attention to their scars. The surgical scar served as a constant reminder of their illness and weakness, intensifying their fears of future complications associated with their CHD, as a 13-year-old boy said, "When I have a bath or take my clothes off I always remember my illness."

Some children expressed feelings of dissatisfaction about their short stature and thin body. Having an altered physical appearance and perceiving themselves as odd may have a vital role in developing an impaired identity, which could set these children apart from their peers and affect their social interaction with their peers, as a 15-year-old boy said, "I want to become like other boys, I hope to be tall and fat."

*Worries about marriage opportunities.* This subtheme refers to the decrease of children's chances of getting married in the future, because of the CHD due to altered physical appearance and physical symptoms. Some parents reported that the open-heart surgery had distorted their daughter's appearance and affected her social image. This was reported to happen for two reasons for girls with CHD: First, the girls and their parents expressed their worries and fears that the girl would be unable to assume the traditional role expected of her because she would be less capable of pregnancy and childbirth. Second, they feared passing on their CHD to their future children.

I am afraid that I couldn't carry a normal pregnancy and childbirth in the future. I also fear that my CHD will pass to my children in the future as it is a hereditary disease. I don't want to have children with CHD as I couldn't tolerate the idea.  
(Girl, 16 years old)

For boys, some parents believed that their son's chance of getting married and having a family would be mainly affected by diminished physical capacity, which might affect his ability to assume his traditional role as being head of the household.

I'd like to marry him off at 19 or 20, it doesn't matter. I fear that he will get worse at the age of 30. Marriage needs muscular or physical effort; I can't guarantee what will happen. He had the operation at the age of four. We don't know what will happen after this. I want him to live a stable life and to have sons just like anyone else. He will not be able to marry and have children at the age of 30 as his health condition will be poor and he will not be able to work.  
(Father of a 17-year-old boy)

### *Limitations in Access to Health Care Due to the Political Situation*

This theme represents how children with CHD and their parents faced barriers and difficulties regarding access to health care facilities, and social isolation when hospitalized in Israel and East Jerusalem due to mobility restrictions and closure imposed by the political situation. Parents felt powerless to counteract the occupiers' restrictions on entering Jerusalem, as they were aware of it being out of their hands. However, some of parents managed to overcome these obstacles and found alternative ways to handle them at that time, but their worries remained about the possibility of their child facing complications in the future and needing more advanced care.

*Barriers in access to health care.* This subtheme is related to the challenges and difficulties the children with CHD and their parents faced to access to health care facilities. Their access was limited by several barriers, some due to the occupation and mobility restriction, as children and their parents required permission from the Israeli authorities to travel from the West Bank to reach more specialized hospitals in Jerusalem or Israel.

On some occasions, the permit for both parents was denied, and on other occasions, just the father's permit was denied, with no reason given by the Israeli authorities; so some families made a difficult and dangerous decision to enter Israel illegally, to accompany their child in need of open heart surgery or cardiac catheterization as a mother of an 11-year-old girl said, "Neither my husband nor I got permission to join our daughter so I entered Jerusalem illegally as I didn't have a permit." Another father of a 16-year-old girl said, "I couldn't accompany her during her surgery as permission to enter Israel was rejected by the Israeli authorities."

Sometimes, the fathers were risking their lives if caught by the Israeli authority. Denying permits to parents of children with CHD intensified suffering for these families and made them less able to support each other. Some parents who were working in the West Bank faced more economic hardship, especially those who entered Jerusalem without permits and were afraid to return back to the West Bank again because of the risks. This sometimes led to unemployment because they failed to appear at work.

Parents reported difficulties getting insurance cover from the Palestinian MOH, and described how this process was delayed on some occasions by the bureaucratic system. The lack of specialized hospitals was another challenge for some of the parents. Doctors referred children who were in need of more advanced treatment, such as open-heart surgery and cardiac catheterization to Israel and East Jerusalem, because hospitals in the West Bank are sometimes not sufficiently equipped to treat these children.

The political status was very bad in Bethlehem city because of the Israeli invasion and there were many injuries. His father was sent from place to place and from person to person in the ministry of health to get the transfer, the roads were closed, and it was dangerous and difficult to reach us in the hospital because of the indiscriminate shelling. (Mother of a 16-year-old boy)

*Social isolation when hospitalized.* This subtheme is related to feelings of social isolation due to being separated from the family and the language barrier. Closure and Israeli checkpoints were some of the main struggles parents faced when their children needed more specialized or advanced care outside the West Bank. Some mothers reported difficulties and lack of support as they were alone with their children at Israeli hospitals for weeks because their family members did not get permission to visit them and to be with them during that difficult period.

I needed my husband and my family beside me. Because we Arabs usually help each other, imagine the situation. During that month, I didn't see any one, my husband or my family, because they couldn't enter Jerusalem because of the blockade. (Mother of an 11-year-old girl)

These parents also reported difficulties in communicating with health care providers at Israeli hospitals, as they did not receive sufficient information about their children's medical condition due to language barriers.

I can't speak Hebrew or English so I couldn't contact the health team or people in the hospital. It was catastrophic and I was alone, I didn't know how to behave and to know more about my daughter, I waited patiently for Arab workers in the hospital who knew about my daughter's case. (Mother of a 10-year-old girl)

## Discussion

This study provided insights into how children with CHD and their parents experienced their daily life in the Palestinian West Bank. The study described how these children and their parents were highly affected by the sociocultural conditions as well as values and beliefs about chronic disease, which put them under social and emotional pressure, and how they tried to face barriers and manage challenges they encountered in their daily life. This study contributes to a deeper understanding of how political as well sociocultural conditions interact and affect people's resources and management of a vulnerable situation, which is essential for health care providers and for policy makers.

One of the findings in this study was that children with CHD believed that the society and others perceived them in a negative and judgmental way. These negative attitudes and reactions of others in the community could influence their self-perception and leave them unsupported. Social stereotyping and emotional aspects of living with CHD may influence children's and parents' coping behaviors and exacerbate their social isolation and marginalization. This finding is in line with a previous study, which emphasized the effect of the meaning of the disease could be as significant as suffering from the disease symptoms themselves (Weiss, Ramakrishna, & Somma, 2006).

Children with CHD and their parents shared some experiences such as stigmatization and social constraints with children with other chronic illnesses such as diabetes and thalassemia (Al-Awamreh, 2014; Elissa, Bratt, Axelsson, Khatib, & Sparud-Lundin, 2017; Mufti, Towell, & Cartwright, 2015). Stigma is socially constructed and acceptance of persons who are different from the general population varies among societies. Some phenomena may possibly expose a person to stigmatization in a certain society, whereas the same phenomena may be acceptable in another society or culture (Abdullah & Brown, 2011). In Palestine, children with CHD and their parents seem to struggle with negative social reactions. When one family member experiences stigma, the whole family is affected. In the Arab Muslim culture, chronic diseases continue to be viewed as a matter of shame and that the individual situation reflects on the entire family (Al Khateeb, Al Hadidi, & Al Khatib, 2014; Hammad, Kysia, Rabah, Hassoun, & Connelly, 1999). In the present study, families wished to hide their children's illness from disclosure, because they feared that people would view the condition as a sign of a hereditary defect. This might affect the social standing and marriage ability of all associated family members. Family stigma negatively impact family members, enhancing stress and social isolation and affecting their quality of life (Park & Park, 2014). This is consistent with a study conducted in Jordan among parents of children with thalassemia who found that living with thalassemia carried stigma and shame as a consequence of the chronic illness (Al-Awamreh, 2014).



Different strategies can be adopted by policy makers and health care providers to combat stigma by providing an appropriate educational program that focuses on symptoms, etiology, and implications of CHD. A chronic illness may result in discrimination, and disclosing it would increase social exclusion. Furthermore, Berghammer, Dellborg, and Ekman (2006) discussed the dilemma around whether to disclose CHD or not to others. The participants in their study feared rejection and exclusion, and many of them reported difficult experiences when they disclosed their CHD to others.

When the ability of children with CHD and their parents to control the illness and its consequences was limited, they sought spiritual solace by relying totally on God's strength. Their religious faith empowered them to fulfill God's divine destiny for their lives. All participants in this study were Muslims, and the perception that the CHD was their spiritual fate was prevalent. This finding is consistent with various studies conducted on participants with different chronic illnesses, such as heart disease and cancer, in different Arab and Islamic countries (Al-Azri, Al-Awisi, Al-Rasbi, & Al-Moundhri, 2014; Najafi Ghezjeljeh & Emami, 2014; Rahnama, Khoshknab, Maddah, Ahmadi, & Arbabisarjou, 2016). Health and wellness of Muslims is strongly influenced by their religious faith and beliefs (Ypinazar & Margolis, 2006). Accordingly, valuing and taking care of the human body, striving to be in a good health, and seeking health care when sick, stem from the Islamic teachings about health (Odeh Yosef, 2008).

In a study conducted in Jordan among Muslim patients with heart disease, participants believed that their faith helped them to accept their illness and to cope with it in a positive way (Nabolsi & Carson, 2011). Moreover, different studies have emphasized the vital role of religious beliefs on the mental and physical health of patients with chronic illness and how their religious faith empowers them to enhance their health and to make healthier choices (Babamohamadi, Negarandeh, & Dehghan-Nayeri, 2011; Hosseini, Sharif, Ahmadi, & Zare, 2010; Nabolsi & Carson, 2011). It is worth mentioning that the phenomenon of finding support in religious faith not only is not limited to Islam but also appears in people with chronic illness from other religious backgrounds, such as Christianity, Hinduism, and Judaism (Reynolds, Mrug, & Guion, 2013; Selway & Ashman, 1998; Sira et al., 2014; Ypinazar & Margolis, 2006). From another point of view, having a chronic illness may lead to aggravated guilt feelings, religious struggle, and the perception of illness as a sin or a punishment by God. Therefore, religiosity could also inhibit children's ability to cope with their chronic illness, have a negative impact on their well-being, and result in poor quality of life (Drutchas & Anandarajah, 2014; Reynolds, Mrug, Hensler, Guion, & Madan-Swain, 2014).

One of the notable findings in this study was the fact that children with CHD were engaged in risk-taking behavior such as participating in strenuous physical activities to keep up with their peers. Although they were aware of the risk, they chose to jeopardize their health to counteract potential discrimination and judgment by their peers. This could be due to a lack of peer support and misunderstanding, which intensify the suffering of children with CHD. Engaging in risky activities or hiding signs of CHD to conform to “normal” behavior were strategies that were adopted by the children to cope with illness. This result is supported by Claessens et al. (2005) who found that patients with CHD strived to have a life that is as normal as possible, making normalization the core concept of their experience. Supportive peer relationships among adolescents with CHD were found to have had a positive impact on these adolescents’ self-identity and self-worth (Rassart, Luyckx, Apers, Goossens, & Moons, 2012). Therefore, health care providers and teachers should be aware of the necessity of enhancing peer acceptance and acknowledgment of children with CHD, which may facilitate their coping and minimize their suffering.

Given that the Arab society is traditional and patriarchal, it is not surprising that these girls with CHD perceived that they no longer fitted the social norms of beauty, feeling less attractive and even ashamed of their appearance. As found in this study, the impact of CHD on the body made the children, in particular the girls, vulnerable to sociocultural values; and, attitudes toward children with chronic illness and their parents’ goal to get them married in the future were affected. Furthermore, to successfully maintain the female role assigned by Arab society, it is imperative that the wife should be healthy enough to bear pregnancy and childbirth without any risks and take care for children and household responsibilities. Therefore, CHD could jeopardize the Arab woman’s ability to maintain her assigned role as a mother and caregiver, and it could be perceived not only as a chronic disease but also as a possible threat to the woman’s standing as a family and society member. The same phenomenon was found in young women with thalassemia, who had difficulties getting a marriage partner due to sociocultural norms (Al-Awamreh, 2014).

This study also highlighted the challenges that children with CHD and their parents faced as a result of political conditions, especially the occupation. Although the families are aware of the higher level of services that will be provided in the Israeli hospitals, they may avoid sending their children to those hospitals because of the challenges in obtaining permits and crossing borders to access health services. The report that was conducted by WHO (2014b) concluded that the exclusive use of the Hebrew language in Israeli hospitals can influence the patient’s right to give their informed consent, to ask questions, and to follow recommended medical procedures.

This ultimately will threaten children's lives, particularly those who need advanced care. Bearing in mind that most of the children with CHD and their families in this study in the West Bank struggled to obtain permission to enter Jerusalem, but for those who succeeded in getting the permit, the entire treatment journey was humiliating and hard for them to bear. Patients have to take long routes around the separation wall to travel a short distance, to walk through Israeli checkpoints, to go through metal detectors and bars, and to bear long delay at barriers, which can be a tiring journey for critically ill and disabled patients (WHO, 2014b). This experience is supported by a study conducted among women with breast cancer in the occupied Palestinian territories, in which participants reported how they were alone and separated from their families during treatment in the East Jerusalem hospital because none of their relatives got permits to be with them (Hammoudeh, Hogan, & Giacaman, 2016). Parents who have social support are able to better cope with their child's illness and have improved psychosocial outcomes (Fletcher, 2011; Rini et al., 2008). Separation during critical family events such as child hospitalization and heart surgery changes family's pattern of functioning, disrupts the normal routines of daily life, and changes roles within the family unit (Hagstrom, 2017; Jones, 2015). As the mother in the Palestinian society is the primary caregiver, she usually stays with the child at the hospital, whereas the father and older siblings adopt the mother's role at home. It has been described in previous research that mothers experienced "being split" between their hospitalized child and siblings at home (Hagstrom, 2017). In addition, Hagstrom (2017) highlighted the significant role of separation in the mother's experiences of stress and feelings of guilt about their responsibilities. Palestinian fathers' inability to be with their ill children and wives during critical events makes them feel confused and alone as a parent.

### *Limitations*

All the participants in this study were Muslims; children and parents with other religious backgrounds might have different experience and perceptions about living with CHD in Palestine. In addition, the sample size is small but, in accordance with qualitative research, data saturation was considered to be reached. This study includes only children with CHD and their parents, but experiences and perceptions of the extended family and members of the local community were not explored, although they might have different experiences and perceptions about children with CHD. Furthermore, translation of interviews from Arabic to English was one of challenges faced by the research team to maintain the real meanings. To

meet this challenge, close attention was paid to preserving the original meaning when translating the text into English.

### *Implications for Future Research*

The findings of this study underscore the sociocultural burden on daily life of children with CHD and their parents. To optimize family nursing care/interventions and to gain a more comprehensive understanding of the complexity of stigma and its impact on the whole family function, relationships, structure and coping behavior, further research is needed. Another area that needs further attention is exploring the healthy sibling's, extending family and members of local community, experiences. In addition, further research is needed to evaluate the effectiveness of the services and resources available for children with CHD and their families in the West Bank, Palestine.

### *Implications for Practice With Families*

The findings of this study can improve health care providers' understanding of the experiences of daily life for children with CHD and their parents to meet the families' needs; the health care providers would then be better equipped to help these families to overcome barriers and manage challenges to improve their health, well-being, and quality of life lives by incorporating CHD in their everyday life. Furthermore, the findings highlight the importance of raising awareness among the public and among schoolteachers about CHD to combat the negative consequences associated with sociocultural values and misconceptions about chronic illness. Moreover, this study could enhance the capacity of policy makers in the West Bank of Palestine to take the necessary measures to overcome the stigma associated with CHD in children. This study highlighted some positive effect of religious beliefs and faith in facilitating the coping with illness and, therefore, policy makers and health care providers have to provide effective and constructive measures such as religious counseling. The findings of this study could be transferable to the context of children with CHD and their parents living in similar sociocultural contexts and conditions, such as in other Arab Muslim societies and communities around the world.

The International Family Nursing Association (IFNA) has developed an IFNA Position Statement on Generalist Competencies for Family Nursing Practice, and recommends research to support family nursing assessment, intervention, and care with families (IFNA, 2015). This study identified the cultural and contextual nature of the Palestinian families, and therefore, the findings could be utilized to implement family nursing practices for children and families experiencing CHD in Palestine.

## Conclusion

Stigma and social stereotyping beliefs led to psychosocial difficulties for children with CHD and their parents. This study highlighted the impact of sociocultural conditions, values, beliefs, and social pressure on the everyday life of children with CHD and their parents due to insufficient knowledge and misunderstandings about CHD in the Palestinian society. Both boys and girls were concerned about limited marriage opportunities because of social stigma. However, this study highlighted the supportive role of faith and religious beliefs in facilitating their coping with the chronic illness. Furthermore, this study has illustrated how the political situation in the West Bank has led to economic difficulties and restricted access to specialized health care for families having a child with CHD, and thereby, further threaten the child's and the families' health and well-being.

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## Author Biographies

**Kawther Elissa**, RN, MSN, is a lecturer in nursing and coordinator of a child health nursing course at College of Health Professions, Al-Quds University, Abu Dies Campus, Jerusalem, Palestine. She is currently a doctoral student at the Institute of Health and Care Sciences, Sahlgrenska Academy, University of Gothenburg, Sweden. Her research focuses on child health nursing and daily life experiences in children with chronic diseases and their families. Her recent publications include "Societal Norms and Conditions and Their Influence on Daily Life in Children With Type 1 Diabetes in the West Bank in Palestine" in *Journal of Pediatric Nursing* (2017, with E.-L. Bratt, A. B. Axelsson, S. Khatib, & C. Sparud-Lundin).

**Carina Sparud-Lundin**, RN, PhD, is a senior lecturer and associate professor, Institute of Health and Care Sciences, Sahlgrenska Academy, University of Gothenburg, Sweden. Her research focuses on health, well-being, and experiences of professional care and family support in people with Type 1 diabetes and other chronic conditions during different transitions in life. Her recent publications include "Health Care Providers' Attitudes Towards Transfer and Transition in Young Persons With Long Term Illness—A Web-Based Survey" in *BMC Health Services Research* (2017, with M. Berghammer, P. Moons, & E.-L. Bratt) and "Societal Norms and Conditions and Their Influence on Daily Life in Children With Type 1 Diabetes in the West Bank in Palestine" in *Journal of Pediatric Nursing* (2017, with K. Elissa, E.-L. Bratt, A. B. Axelsson, & S. Khatib).

**Åsa B. Axelsson**, RN, PhD, is an associate professor and senior lecturer, Institute of Health and Care Sciences, Sahlgrenska Academy at University of Gothenburg and Division of Cardiology, Sahlgrenska University Hospital, Sweden. Her research area is cardiovascular nursing with emphasis on cardiac arrest and resuscitation. Further research areas include pediatric nursing related to hypertrophic cardiomyopathy and children living with chronic disease and/or disability. She has an extensive experience in qualitative research. She has been a visiting lecturer at Al-Quds University, Palestine, for 3 weeks annually since year 2012. Her recent publications include "From Feeling Broken to Looking Beyond Broken: Palestinian Mothers' Experience of Having a Child With Spina Bifida" in *Journal of Family Nursing* (2017, with M. Nahal, H. Wigert, & A. Imam), "Societal Norms and Conditions and Their Influence on Daily Life in Children With Type 1 Diabetes in the West Bank in Palestine" in *Journal of Pediatric Nursing* (2017, with K. Elissa, E.-L. Bratt, S. Khatib, & C. Sparud-Lundin), "The Experience of Being Diagnosed With Hypertrophic Cardiomyopathy Through Family Screening in Childhood and Adolescence" in *Cardiology in the Young* (2012, with E.-L. Bratt, C. Sparud-Lundin, & I. Ostman-Smith).

**Salam Khatib**, RN, PhD, is a senior lecturer and assistant professor, Department of Nursing, Faculty of Health Professions, and the coordinator of master's studies at the Department of Nursing at Al-Quds University, Jerusalem, Palestine. She is also the coordinator of psychiatric and mental health nursing courses at Al-Quds University, Faculty of Health Professions. An important theme in her work is gender-based violence and particularly honor killing. She has an interest in qualitative research such as grounded theory and content analysis. However, she has also been committed to using several different research methods in her work such as experimental studies and cross-sectional studies. Her recent publications include "Societal Norms and Conditions and Their Influence on Daily Life in Children With Type 1 Diabetes in the West Bank in Palestine" in *Journal of Pediatric Nursing* (2017, with K. Elissa, E.-L. Bratt, A. B. Axelsson, & C. Sparud-Lundin).

**Ewa-Lena Bratt**, RN, PhD, is a senior lecturer at the Institute of Health and Care Sciences, University of Gothenburg, Sweden. She is primarily involved in research on transitions in health care. She is also a nurse specialized in pediatric health care at the Department of Pediatric Cardiology, Queen Silvia Children's Hospital, Gothenburg, Sweden. Her recent publications include "Societal Norms and Conditions and Their Influence on Daily Life in Children With Type 1 Diabetes in the West Bank in Palestine" in *Journal of Pediatric Nursing* (2017, with K. Elissa, A. B. Axelsson, A. B. Axelsson, S. Khatib & C. Sparud-Lundin), "Health Care Providers' Attitudes Towards Transfer and Transition in Young Persons With Long Term Illness—A Web-Based Survey" in *BMC Health Services Research* (2017, with C. Sparud-Lundin, M. Berghammer, & P. Moons), and "Adolescents With Congenital Heart Disease: Their Opinions About the Preparation for Transfer to Adult Care" in *European Journal of Pediatrics* (2017, with A. Burstrom et al.).