

# Determinants of successful medical education of caregivers of children with congenital heart diseases



Ahmad S. Azhar<sup>a,\*</sup>, Zaher F. Zaher<sup>a</sup>, Noran M. Abu-Ouf<sup>a</sup>, Jameel Al-Ata<sup>a</sup>, Sara Taisir A. Alsheblie<sup>a</sup>

<sup>a</sup> Pediatric Department, Faculty of Medicine, King Abdulaziz University, Jeddah,

<sup>a</sup> Saudi Arabia

**Objective:** To assess the implementation and efficiency of medical education among the caregivers of children with congenital heart disease (CHD) and to investigate its success factors.

**Material and method:** A cross-sectional study was conducted from February 2014 to March 2014 in a tertiary health-care center. Study included 120 caregivers of children with CHD visiting the Paediatric Cardiology Clinic that included 93% mothers, aged 31.72 ± 6.67 years, 38.3% Saudi citizens and 45.0% had a high educational level. Caregivers were interviewed through a semi-structured questionnaire that included socio-demographic data of participants and demographic and clinical data of patients; awareness about the diagnosis and self-assessed understanding of the disease; disease dimensions explained, educational material used and efficacy of whole medical education received in alleviating caregivers' anxiety.

**Results:** Of children who had CHD, around 42.5% were males aged 5.65 ± 3.99 years and 37.3% had ventral septal defect, 14.4% had atrial septal defect and 19.5% had a complex CHD. Study results showed that 83.3% of caregivers were aware of the correct diagnosis and 64.2% had good understanding of the nature and effect of the disease. Frequently explained disease dimensions were impact on child's growth (65.8%), complications (57.5%), and outcomes (55.0%). Least frequently explained dimensions were those related to infective endocarditis (IEC) including risk factors (15.8%), prophylaxis (17.5%), complications (19.2%) and symptoms (22.5%). The whole medical education received was efficient to enable good understanding of the disease and alleviate anxiety in 70.8% and 62.5% of the cases, respectively. Time dedicated to educate, use of illustrating educational materials, explaining various disease dimensions (aetiology, complications, prognosis, long-term management, etc.) and the number of dimensions explained were all significant predictors for both good understanding of the child's disease and anxiety relief among caregivers.

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\* Corresponding author at: Pediatric Department, Faculty of Medicine, King Abdulaziz University, Jeddah 21589, Saudi Arabia.  
E-mail addresses: [aazhar@kau.edu.sa](mailto:aazhar@kau.edu.sa), [azcardio@hotmail.com](mailto:azcardio@hotmail.com) (A.S. Azhar).



P.O. Box 2925 Riyadh – 11461KSA  
Tel: +966 1 2520088 ext 40151  
Fax: +966 1 2520718  
Email: [sha@sha.org.sa](mailto:sha@sha.org.sa)  
URL: [www.sha.org.sa](http://www.sha.org.sa)



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## Introduction

Parents of children with congenital heart diseases (CHDs) are often confronted to take critical decisions regarding their child’s care, as a part of their sustained role of caregivers [1,2]. An illustrative example is the consent they should give prior to reparative cardiac surgery, which assumes good understanding of the patient’s cardiac condition as well as of all available therapeutic options [3].

Caregivers’ efficient input in terms of their children’s care depends fundamentally on the accuracy of their knowledge about the disease, its symptoms, short- and long-term complications (such as endocarditis), and the preventive rules, besides having good judgmental capacities in critical situations [4,5].

Caregivers’ support is undeniably an advantage for the patients’ quality of life [6]. According to previous data, the level of parents’ knowledge about the disease plays a key role in the quality of life of the patient, and good understanding of the disease would probably lead to more appropriate care [7]. A study by Blue et al. [8] demonstrated that improving parents’ knowledge by means of individualized genetic counseling reduced their diagnosis-related anxiety, depression, and stress, which would result in better contribution of the parents to their child’s care.

The type and quality of information provided by healthcare professionals constitute the cornerstone of parental knowledge, and in many situations, it is the precursor of the decision-making process [9]. However, because of many interfering factors, such as the personal level of understanding, misinterpretations, and retention of relevant information, parents’ accurate and genuine knowledge of the disease may be surprisingly deficient [5,10,11].

These data emphasize the multifaceted educative role of healthcare professionals in educating caregivers of pediatric CHD patients, which should be much broader than simply providing medical information. Healthcare professionals should regularly ensure that the caregiver’s understanding is appropriate for making timely decisions and compatible with secure long-term patient care [4,12]. Furthermore, caregivers should be given opportunities to ask questions and provided with sources of additional help and advice [13], as they are often keen to learn more [11].

With this study, we wanted to explore the pattern of medical education provided by healthcare

Abbreviations	
ASD	Atrial septal defect
CHD	Congenital heart disease
IEC	Infective Endocarditis
KAUH	King Abdulaziz University Hospital
OR	Odd-ratio
SD	Standard Deviation
SPSS	Statistical Package for Social Sciences
VSD	Ventricular septal defect

professionals to caregivers of children with CHDs, including types of medical information provided (i.e., disease dimensions explained), time dedicated, and educational materials used, and to investigate further factors for successful medical education, which is defined as the efficacy of the whole medical education received in enabling good understanding of the nature and effects of the disease among caregivers and in alleviating their anxiety.

## Materials and methods

This cross-sectional study was conducted in King Abdulaziz University Hospital, Jeddah, Saudi Arabia, over a period of 2 months (February 2014–March 2014). Convenience sampling was used to recruit adult caregivers (aged 18–52 years) who presented during the study period at the Paediatric Cardiology Clinic of King Abdulaziz University Hospital for follow-up with their pediatric CHD patient. The nature and objectives of the study were explained to all caregivers, and those who were eligible to participate were invited for an interview. Participants were free to withdraw from the interview at any time and were registered as dropouts. The Research Ethics Committee of the Faculty of Medicine in King Abdul Aziz University approved the research.

### Questionnaire

A structured questionnaire, written in English and translated to Arabic, was employed to collect data from each participant. The questionnaire included a total of 25 questions divided into four parts: (1) sociodemographic data of participants such as age, educational level, and nationality, and demographic and clinical data of diseased children such as age, sex, accurate diagnosis (type of CHD), age at diagnosis, and number of cardiology visits per year; (2) autoassessed knowledge of caregivers about the disease, including the two items—awareness of the accurate diagnosis, and

Table 1. Demographic and clinical characteristics of diseased children and their caregivers.

Variable/values	Frequency/mean	Percentage/SD
<i>Child</i>		
Age (range = 0.5–18.0 y)	5.65	3.99
Sex		
Male	51	42.5
Female	69	57.5
Nationality		
Saudi	46	38.3
Non-Saudi	74	61.7
<i>Clinical data</i>		
Lifestage at diagnosis		
Antenatal	3	2.5
At birth	59	49.2
Newborn (<1 y)	19	15.8
Infancy (1–2 y)	15	12.5
Childhood	24	20.0
Type of CHD		
VSD	44	37.3
PDA	4	3.4
ASD	17	14.4
AVC	8	6.8
PS	7	5.9
TOF	8	6.8
Complex CHD	23	19.5
Other	7	5.9
Number of hospital visits per year (range = 1–8 visits)	3.23	2.24
Number of echos per year (range = 0–6 echos)	2.34	2.63
Catheterization performed	18	15.3
<i>Caregiver</i>		
Age (range = 18–52 y)	31.72	6.67
Relation with child		
Mother	112	93.3
Father	2	1.7
Other (aunt)	3	2.6
Nationality		
Saudi	48	40
Non-Saudi	72	60
Educational level		
Illiterate	19	15.8
Elementary & middle school	14	11.7
Secondary school	33	27.5
University or higher	54	45.0

ASD = atrial septal defect; AVC = atrioventricular canal; CHD = congenital heart disease; PDA = patent ductus arteriosus; PS = pulmonary stenosis; SD = standard deviation; TOF = tetralogy of Fallot; VSD = ventricular septal defect.

good understanding of the nature and effects of the disease; (3) dimensions of the disease explained by healthcare professionals, such as etiology, complications, long-term management, medications, therapeutic procedures, etc.; and (4) means employed for caregivers' education, such as the function of the professional who provided the information (consultant or resident), educational materials used (verbal, drawing, leaflets, etc.), and time dedicated (<5 minutes, 6–10 minutes, or >10 minutes), in addition to assessment of caregivers' satisfaction about the education provided, including satisfaction about the clarity of

the medical information, sufficiency of time dedicated, preference regarding educational material used, adequacy of the medical information to enable caregivers take care of the children with CHDs, and whether it was useful to alleviate caregivers' anxiety. Items from parts 2, 3, and 4 were based on a relevant review of literature in addition to clinical sense, and underwent face and content validity by authors.

#### Statistical analysis

Data were analyzed using SPSS, version 21 (IBM SPSS Statistics for Windows, released 2012; IBM

Table 2. Knowledge of caregivers and medical education received from healthcare professionals.

Variable/values	Frequency	Percentage <sup>a</sup>
<b>Knowledge</b>		
Caregiver is aware about the diagnosis	100	83.3
Caregiver has good understanding of the nature and effects of the disease	77	64.2
<b>Disease dimension or type of education received</b>		
Complications of the disease explained	69	57.5
Etiology of the disease explained	50	41.7
Effects of the disease on growth explained	79	65.8
Outcome of the disease on caregiver explained	66	55.0
Long-term prognosis explained	50	41.7
Nature of catheterization explained (N = 18)	13	72.2
Complications of catheterization explained (N = 18)	12	66.7
Effects of the medication explained	41	34.2
Side effects of the medication explained	37	30.8
Caregiver educated for long-term management	52	43.3
Type of surgery explained	47	39.2
Complications of surgery explained	32	26.7
Caregiver informed about IEC	39	32.5
Symptoms of IEC explained	27	22.5
Risk factors of IEC explained	19	15.8
Complications of IEC explained	23	19.2
Prophylaxis of IEC explained	21	17.5

IEC = infective endocarditis.

<sup>a</sup> Percentages were calculated out of valid observations (missing data excluded).

Corp., Armonk, NY, USA). Descriptive statistics was used to analyze frequencies and percentage on categorical variables, and means and standard deviations (SDs) on continuous variables. Caregivers were divided into two groups: those who declared having good understanding of the nature and effects of the disease, and those who declared not having good understanding. Demographic and clinical factors as well as factors related to education received were compared between the two groups. The association between categorical variables was analyzed using chi-square test or Fisher's exact test, as appropriate, while a comparison of means was performed using independent *t* test. Binary logistic regression analyses were carried out to analyze predictors for good understanding of the child's disease and efficacy of education received in alleviating caregivers' anxiety. Statistical significance was set for  $p < 0.05$ .

## Results

### Characteristics of the population

This study included 120 caregivers aged between 18 years and 52 years (mean  $\pm$  SD = 31.72  $\pm$  6.67 years), the majority of whom were mothers (93.3%), 1.7% fathers, and 2.6% aunts. Assessment of educational level showed that 54 (45.0%) of the caregivers were highly

educated, having a university degree or more, and 19 (15.8%) were illiterate (Table 1).

### Demographic and clinical characteristics of the diseased children

Diseased children were aged 0.5–18 years (mean  $\pm$  SD = 5.65  $\pm$  3.99 years), and 51 (42.5%) of them were males and 74 (61.7%) were of a non-Saudi nationality. Characteristics of the disease showed that the majority of children were diagnosed at birth (49.2%) or during the 1<sup>st</sup> year of their life (15.8%), and only three (2.5%) cases were diagnosed prenatally. Ventricular septal defect was the most common diagnosis reported in 44 (37.3%) of total cases, followed by complex CHDs in 23 (19.5%) cases, and atrial septal defect in 17 (14.4%) cases. Other clinical characteristics showed an average number of hospital visits per year (3.23; range = 1–8), and catheterization was performed in 18 (15.3%) of the children (Table 1).

### Knowledge of caregivers and medical education received

A total of 100 (83.3%) caregivers were aware of the diagnosis of their diseased child, while 77 (64.2%) declared having good understanding of the nature and effects of the disease. The type of medical information that was most frequently declared to be provided by health professionals to caregivers was the effect of CHD on the child's

Table 3. Means and efficacy of the information and education provided for the caregivers.

Variable/values	Frequency/mean	Percentage <sup>a</sup> /SD
Who provided education to the caregiver?		
Consultant	111	92.5
Resident	3	2.5
Does not know	6	5.0
Was the medical information clear enough?		
No	37	30.8
Yes	83	69.2
Time dedicated to explain child's disease (min)		
<5	25	21.6
6–10	53	45.7
>10	38	32.8
Was the time dedicated enough?		
No	46	38.3
Yes	74	61.7
Educational material used		
Verbal	59	49.6
Drawing	44	37.0
Leaflets	8	6.7
Electronic material	2	1.7
Other (echo image)	6	5.0
Preferred educational material		
None	14	12.3
Verbal	2	1.8
Drawing	47	41.2
Leaflets	22	19.3
Electronic material	29	25.4
Was the medical education received adequate to enable caregivers take care of the child with CHD?		
No	35	29.2
Yes	85	70.8
Was the education provided enough to alleviate caregiver's anxiety?		
No	45	37.5
Yes	75	62.5

CHD = congenital heart disease; SD = standard deviation.

<sup>a</sup> Percentages were calculated out of valid observations (missing data excluded).

growth (65.8%), followed by complications of the disease (57.5%) and outcome of the disease on caregivers (55.0%). The information that was less frequently provided was related to infective endocarditis (IEC), including risk factors (15.8%), prophylaxis (17.5%), complications (19.2%), and symptoms (22.5%), as per the participant's declaration. Internal consistency was tested for this part of the questionnaire assessing knowledge and explanations provided to caregivers, finding excellent reliability with a Cronbach  $\alpha = 0.916$  (Table 2).

#### Means and efficacy of medical education provided for caregivers

Medical information was provided by a consultant in 92.5% cases and was evaluated by the caregiver as being clear in 69.2% of cases. Time dedicated to caregivers' education was <5 minutes in 21.6% and >10 minutes in 32.8% of cases, and

was judged to be sufficient in 61.7% of cases. In 37.0% of cases, the counseling health professional used a drawing to explain the disease, while leaflets and electronic material were used in 6.7% and 1.7% of the cases, respectively. The use of illustrative educational materials including drawing, leaflets, or electronic material was appreciated by 85.9% of the caregivers. The whole medical information received was judged as adequate to enable them take care of the children with CHDs by 70.8% of the caregivers and was enough to alleviate anxiety in 62.5% of them (Table 3).

#### Factors associated with caregivers' knowledge about the child's disease

Demographic factors associated with good understanding of the nature and effect of the disease included Saudi nationality ( $p = 0.001$ ) and a high educational level of the caregiver ( $p < 0.001$ ).

Table 4. Factors associated with caregivers' good understanding of the nature and effect of the child's disease.

Factor/categories	Caregiver has good understanding of the nature and effect of the child's disease				p
	No		Yes		
	F/mean	%/SD	F/mean	%/SD	
<i>Demographic factors</i>					
Child's age	5.46	3.42	5.38	4.04	0.918
Child's nationality					
Saudi	7	15.9	37	84.1	0.002* [F]
Non-Saudi	32	44.4	40	55.6	
Age of caregiver	32.08	6.90	31.36	6.21	0.575
Nationality of caregiver					
Saudi	7	15.2	39	84.8	0.001* [F]
Non-Saudi	32	45.7	38	66.4	
Caregiver's educational level					
Illiterate	14	73.7	5	26.3	<0.001*
Elementary & middle school	8	66.7	4	33.3	
Secondary	3	9.1	30	90.9	
University+	14	26.9	38	73.1	
<i>Clinical factors</i>					
Lifestage at diagnosis					
Antenatal	3	100.0	0	0.0	<0.001*
At birth	20	35.1	37	64.9	
Newborn (<1 y)	0	0.0	17	100.0	
Infancy (1-2 y)	9	60.0	6	40.0	
Childhood	7	29.2	17	70.8	
Type of CHD					
VSD	11	25.0	33	75.0	0.002*
PDA	0	0.0	4	100.0	
ASD	4	26.7	11	73.3	
AVC	2	25.0	6	75.0	
Complex CHD	9	42.9	12	57.1	
PS	2	28.6	5	71.4	
TOF	8	100.0	0	0.0	
Other	1	14.3	6	85.7	
Number of hospital visits per year	2.50	1.56	3.70	2.53	
Number of Echos per year	1.89	1.23	2.54	1.83	0.170
<i>Factors related to caregiver's education</i>					
Time taken to explain child's disease (min)					
<5	15	60.0	10	40.0	0.001*
6-10	17	33.3	34	66.7	
>10	5	13.9	31	86.1	

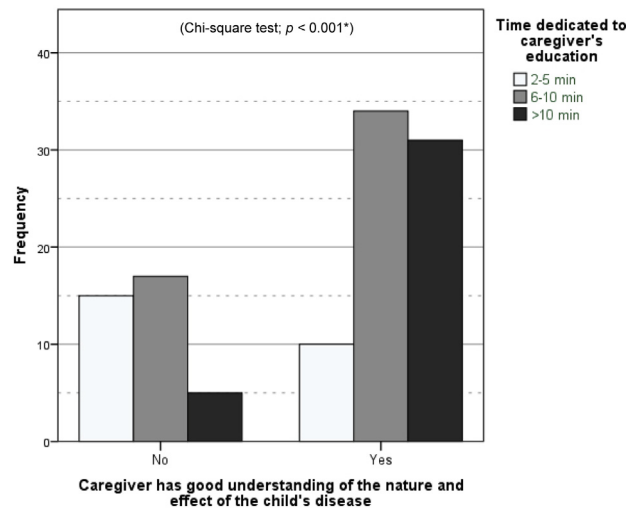
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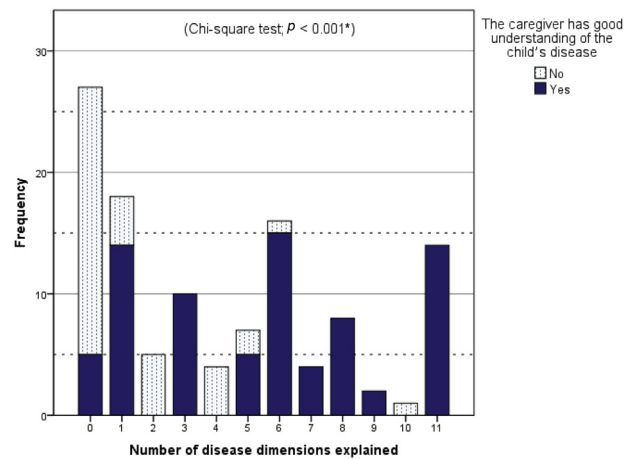
**Table 4 (continued)**

Factor/categories	Caregiver has good understanding of the nature and effect of the child's disease			p
	Yes		% /SD	
	F/mean	% /SD		
Was explanation time enough?				
No	29	63.0	37.0	<0.001*
Yes	10	14.3	85.7	
Explanatory material used				
Verbal explanation	29	52.7	47.3	<0.001*
Drawing, leaflet, e-material, echo image	9	15.0	85.0	
Number of disease dimensions explained (mean ± SD)	1.44	2.26	3.64	<0.001*

ASD = atrial septal defect; AVC = atrioventricular canal; CHD = congenital heart disease; F = significance calculated using Fisher's exact test; PDA = patent ductus arteriosus; Other = pulmonary vessels disease, transposition of great arteries, coarctation of the aorta, mitral valve prolapse; PS = pulmonary stenosis; SD = standard deviation; TOF = tetralogy of Fallot; VSD = ventricular septal defect.



**Figure 1.** Impact of time taken to explain the child's disease on good understanding of the nature and effects of the disease among caregivers.



**Figure 2.** Impact of the number of disease dimensions explained on the good understanding of the child's disease among caregivers.

Regarding clinical factors, the percentage of caregivers who reported having good understanding of the disease was higher for children who were diagnosed in the 1st year of infancy or during childhood (100% and 70.8%, respectively;  $p < 0.001$ ), while it was lower among those with tetralogy of Fallot or complex CHDs (0% and 57.1%, respectively;  $p = 0.002$ ) by comparison with their counterparts. Caregivers who have good understanding of the child's disease had more frequently visited the specialist clinic in comparison with those who do not have good understanding (mean  $\pm$  SD =  $3.70 \pm 2.53$  vs.  $2.50 \pm 1.56$  visits per year;  $p = 0.039$ ). Regarding factors related to caregivers' education, length ( $p = 0.001$ ) and sufficiency ( $p < 0.001$ ) of the time

Table 5. Predictors for good understanding of the nature and effect of the child's disease among caregivers.

Predictor/category	OR	95% CI OR		p
		Inf.	Sup.	
Child's age	0.99	0.90	1.10	0.917
Child's nationality (non-Saudi)	0.24	0.09	0.60	0.002*
No. of visits per year	1.30	1.01	1.68	0.046*
No. of echos per year	1.30	0.89	1.90	0.174
Caregiver's age	0.98	0.93	1.04	0.571
Caregiver's nationality (non-Saudi)	0.21	0.08	0.54	0.001*
Caregiver's educational level				
Illiterate (ref.)	–	–	–	<0.001*
Elementary & middle school	1.40	0.29	6.77	0.676
Secondary	28.0	5.85	134.00	<0.001*
University+	7.6	2.31	25.00	0.001*
Explanation time (min)				
<5 (ref.)	–	–	–	0.002*
6–10	3.00	1.12	8.07	0.030*
>10	9.30	2.70	32.07	<0.001*
Explanatory material				
Verbal explanation (ref.)	–	–	–	–
Drawing, leaflets, e-material, echo image	6.32	2.61	15.31	<0.001*
Disease dimension				
Complications	12.70	4.96	32.50	<0.001*
Etiology	59.53	7.76	465.81	<0.001*
Effects on growth	5.65	2.44	13.09	<0.001*
Outcomes on caregiver	6.03	2.55	14.29	<0.001*
Prognosis	6.60	2.48	17.56	<0.001*
Effect of medication	3.61	1.31	9.99	0.013*
Side effects of medication	8.00	2.22	28.90	0.002*
Long-term management	5.78	2.27	14.70	<0.001*
Type of surgery (N = 66)	0.87	0.20	3.70	0.847
Complications of surgery	3.00	0.75	12.06	0.122
IEC info	5.38	1.90	15.23	0.002*
IEC symptoms	19.37	2.52	149.13	0.004*
IEC risk factors	11.59	1.49	90.46	0.019*
IEC complications	15.20	1.96	117.63	0.009*
IEC prophylaxis	13.33	1.72	103.56	0.013*
Number of disease dimensions explained	1.56	1.29	1.87	<0.001*

CI = confidence interval; IEC = infective endocarditis; Inf. = inferior; OR = odds ratio; ref. = reference category; Sup. = superior.

dedicated to caregivers' education, as well as the number of disease dimensions explained ( $p < 0.001$ ), were positively associated with the percentage of good understanding of the disease among caregivers, in addition to the use of drawing, leaflets, and e-material in comparison with simple verbal explanations ( $p < 0.001$ ).

Results of the previous analysis are presented in Table 4. Chi-square association of the percentage of good understanding among caregivers with time dedicated to education and that with the number of disease dimensions explained are presented in Figs. 1 and 2, respectively.

#### Predictors of good understanding of children's disease among caregivers

Binomial regression analyses showed that good understanding of the child's disease among caregivers was predicted by Saudi nationality in both

diseased child ( $p = 0.002$ ) and caregivers ( $p = 0.001$ ), as well as the number of visits per year ( $p = 0.046$ ), high educational levels of caregivers [secondary ( $p < 0.001$ ) and university+ ( $p = 0.001$ )], longer explanation time, and use of illustrations (drawings, leaflets, e-material, and echo images) to explain the disease ( $p < 0.001$ ). In addition, types of explanation given, including disease complications, etiology, effects on growth, prognosis, education on long-term management, and IEC-related dimension, as well as the number of dimensions explained ( $p < 0.001$ ), were predictors of good understanding of the child's disease among caregivers (Table 5).

#### Predictors for efficacy of provided education in alleviating caregivers' anxiety

Regression analysis of predictors for efficacy of caregivers' education in alleviating anxiety is pre-



Table 6. Predictors for efficacy of education in alleviating caregivers' anxiety.

Predictor/category	OR	95% CI OR		p
		Inf.	Sup.	
Child's age	1.01	0.92	1.11	0.884
Child's nationality (non-Saudi)	0.37	0.16	0.84	0.017*
No. of hospital visits per year	1.29	0.99	1.69	0.058
No. of echos per year	0.95	0.68	1.32	0.755
Caregiver's age	1.04	0.99	1.11	0.142
Caregiver's nationality (non-Saudi)	0.33	0.15	0.75	<0.001*
Caregiver's educational level				
Illiterate (ref)	–	–	–	0.004*
Elementary & middle school	0.55	0.13	2.40	0.427
Secondary	5.11	1.49	17.57	0.010*
University+	2.99	1.02	8.78	0.046*
Explanation time (min)				
<5 (ref.)	–	–	–	<0.001*
6–10	4.60	1.63	12.99	0.004*
>10	21.86	5.64	84.72	<0.001*
Disease dimension				
Complications	5.14	2.31	11.43	<0.001*
Etiology	23.5	6.66	82.96	<0.001*
Effects on growth	2.41	1.11	5.34	0.027*
Outcomes on caregiver	4.25	1.93	9.34	<0.001*
Prognosis	12.00	4.25	33.89	<0.001*
Effects of medication	14.48	4.02	52.07	<0.001*
Side effects of medication	8.00	2.54	25.16	<0.001*
Long-term management	6.66	2.69	16.01	<0.001*
Type of surgery (N = 66)	2.12	0.69	6.52	0.189
Complications of surgery	2.89	0.97	8.59	0.056
IEC Info	5.11	1.93	13.51	0.001*
IEC symptoms	10.75	2.41	48.03	0.002*
IEC risk factors	–	–	–	–
IEC complications	–	–	–	–
IEC prophylaxis	–	–	–	–
Number of disease dimensions explained	1.48	1.26	1.73	<0.001*

CI = confidence interval; IEC = infective endocarditis; Inf. = inferior; OR = odds ratio; ref. = reference category; Sup. = superior.

\* Significant result ( $p < 0.050$ ).

sented in Table 6. Except for child's age ( $p = 0.884$ ), number of hospital visits per year ( $p = 0.058$ ), caregivers' age ( $p = 0.142$ ), elementary education ( $p = 0.427$ ), and type of surgery ( $p = 0.189$ ), all other variables were significant predictors of efficacy of education in alleviating caregivers' anxiety.

## Discussion

The present study shows that only 77% of the participants considered that they had good understanding of the nature and effect of their child's disease and 83.3% were aware of the correct diagnosis. Although based on participants' self-assessment, these proportions concord with the findings of Bulat and Kantoch [10], where 65% of caregivers were able to explain the child's condition, although 91% declared having received sufficient information about the disease. Conversely, Cheuk et al. [14] reported that only 28.8% of the parents exhibited understanding of the nature of the disease.

According to caregivers, the medical information provided by health professionals about the disease of their children was not clear in 30.8% of cases, not adequate to enable them to take care of their children in 29.2% of cases, and not sufficient to alleviate their anxiety in 37.5% of cases. These data indicate relative dissatisfaction among almost one-third of the caregivers about the efficacy and/or practicality of the medical education received. However, caregivers' dissatisfaction may also translate their frustration regarding some interpersonal aspects of the doctor–patient relationship, as the attitude of healthcare professionals when providing such information impacts the emotion and perception of parents and caregivers. An online survey by Hilton-Kamm et al. [9] revealed that parents who did not perceive empathy from the healthcare team were more likely to consult another cardiologist for a second opinion or for long-term follow-up care. The same authors emphasized that health professionals should be careful in choosing appropriate terms

to explain the disease to caregivers and make sure that medical information provided was correctly understood, because frequent misinterpretations are reported.

Among types of medical information received by caregivers, those related to the etiology and prognosis of CHD had the highest impact on anxiety alleviation among caregivers. These two dimensions are particularly interesting, as they refer to causes and consequences of the disease; both may be concerning for parents as they carry feelings of guilt and hopelessness regarding the disease. Psychological impact of the disease on caregivers should be screened and appropriately managed, as they may indirectly impact the child's care. According to some authors, individualized counseling sessions were efficient to improve psychological functions among parents of children with CHDs, including feeling of guilt, shame, and anxiety, in addition to improvement of their knowledge about the disease [8]. Other data suggested that some parents expect more empathy and compassion from healthcare professionals than scientific explanations, and are more inclined towards professionals who share their faith and values [1]. In our religious society, feelings of guilt and shame can be managed by means of spiritual support enjoining acceptance of fate and confidence in God's wisdom. Such an action could be integrated as an ethnopsychotherapeutic approach in the management of distressed parents and families of diseased children, both at the announcement of the diagnosis and in long-term follow-up.

Beyond psychological dimension and attitude of healthcare professionals, there is often an offset between physicians' clinical concerns and information needs among caregivers, or between medical language and the manner medical information is integrated by caregivers. For example, Bulat and Kantoch [10] investigated parents' knowledge about IEC in high-risk pediatric patients and found that 47% of parents reported being aware of IEC, while only 25% could correctly define it, although prophylactic measures were generally comprehended by 71% of them. Furthermore, it was demonstrated that caregivers' learning needs were greater than what cardiologists anticipated, and concerned almost all disease dimensions. Arya et al. [15] found that parents were more particularly concerned with learning to locate the defect on a heart diagram, having more details about the etiology of the disease, and being able to follow up their diseased children, which was in concordance with our findings. In addition, parents from Arya et al.'s series dis-

played interest to learn how to explain the CHD to another physician, what impact the CHD will have on the child's future life, and the number of lifetime surgeries. Other types of medical information reported to be useful from caregivers' point of view included reliable sources for further information, contact information of supportive networks or associations of families of children with CHDs, and health insurance options [9,15].

In this study, the majority of caregivers declared not having received education regarding long-term management of their diseased children (56.7%), and effects (65.8%) and side effects of the treatments prescribed (69.2%), although these constitute crucial information in the long-term management of the disease and were demonstrated to have a significant impact in alleviating caregivers' anxiety. Similar to our observations, a multicenter study showed that almost 56% of parents of children with CHDs were not aware of the necessity of a lifelong cardiac care, stating in 60% of cases that they had never been advised of that [11]. Furthermore, Cheuk et al. [14] reported that almost 93% of parents were not aware of the side effects of medications prescribed to their children.

In this study, the time dedicated by health professionals to explain the disease to caregivers as well as educational materials used was significant predictors of good understanding of the child's disease among caregivers. Probability of good understanding increased significantly when health professionals spent more than 10 minutes or when they used drawings, leaflets, electronic material, or echo images to explain the disease. These observations were comparable with study results of Williams et al. [16] who demonstrated that the extent of parental understanding of the disease was proportional to the period of time spent for parental education. Similarly, according to Hilton-Kamm et al. [9], the manner the information is presented at the time of diagnosis had a significant impact on parents' understanding and future management of their child's CHD. Good understanding of the disease among caregivers was also dependant on the type of CHD. In this series, complex CHDs, tetralogy of Fallot, and patent ductus arteriosus combined with persistent atrial-ventricular canal were associated with lower probability of good understanding of the child's disease, in comparison with other simple CHDs ( $p = 0.002$ ). Similarly, Fernandes et al. [11] found that parents' level of knowledge varied from a diagnosis to another; however, authors reported that tetralogy of Fallot was associated with higher understanding.

Findings of this study emphasize the multifaceted educative role of healthcare professionals towards caregivers of pediatric CHD patients, besides providing them with clear and intelligible information about their child's condition and future management prospects. Inadequate medical advice or inadequately integrated medical information are frequent issues among caregivers of pediatric CHD patients, which entails a risk of negative impact on caregivers' ability to make critical decisions regarding the care of their children [15,17].

As recommended, medical education provided by healthcare professionals to caregivers can be classified into three categories, with a changeable order of priority with regard to the intellectual demand and emotional preparedness of caregivers. Healthcare professionals should be able to not only provide important and relevant medical information, but also ensure effective transmission and understanding by caregivers. Thus, classifying medical education would help prioritize the essential information according to potential aims and contexts, to ensure effective receipt and understanding of the message by caregivers. The proposed categories of medical education are as follows:

(1) *Education for psychosocial issues:* Parents' views and thoughts should be listened to with attention to acknowledge their anxiety and fears, and to identify their specific concerns. As previously discussed, the announcement of the diagnosis may result in negative emotional reactions that can be alleviated by the means of individualized counseling [8]. Some of the questions raised in this category of medical education may appear needless from the physician's view; however, failing to respond satisfactorily to these questions may result in negative perception towards healthcare team's empathy, which may impact the trust relationship and interfere with the quality of follow-up care. On the contrary, passing this step successfully would facilitate reception and understanding of further crucial medical information. Other questions that could be classified in this category of education are socioeconomic issues, such as social assistance, best health insurance options, supportive associations, etc. Such information should be made available in specialized services, in brochure or visit card forms. Moreover, implementing social counseling in either an informative or a supportive

approach can improve the relationship between care team and caregivers, and have a positive impact on families' anxiety and lack of knowledge.

- (2) *Education for clinical and follow-up care issues:* This category of education generally comprises questions in which physicians and caregivers share equal interest. It includes crucial clinical information about the nature and effects of the CHD, lifestyle and prevention rules, exercise limitations, compliance with medications, importance of follow-up visits, and prophylactic measures. Given the importance of this category, healthcare professionals should maintain a proactive awareness-raising approach towards diseased children and their caregivers by continuously assessing their compliance with the recommendations and identifying gaps or misconceptions in their knowledge or understanding of the disease. Additionally, information related to invasive diagnostic or therapeutic procedures, such as catheterizations, or alternative therapeutic options could be included in this type of education, as they are part of informed consent [18].
- (3) *Education for further scientific issues:* Some parents and caregivers may display the need to have deeper understanding of their child's disease and be able to explain it to another doctor or to family members and friends [15]. To satisfy these needs, all caregivers can be provided with reliable information sources, such as websites, articles, and electronic programs, in addition to basic information on what CHDs entail at the time of the diagnosis.

Ideally, information and education strategies should be initiated as soon as possible, even in case of the prenatal diagnosis, to allow parents to become emotionally and knowledgeably prepared to manage their child's condition and consider physicians' advice in a timely manner.

This study was limited by the use of subjective methods including assessment of good understanding of the disease and relief of anxiety, both used as important indicators of successful medical education among caregivers. A more appropriate tool should be used to assess good implementation and efficacy of the medical education.

## Conclusion

Medical education is insufficiently implemented among caregivers of children with CHDs, espe-

cially regarding crucial dimensions of the disease, which may impede daily management of these children and long-term outcomes. Dedicating more than 10 minutes to explain the disease, explaining the etiology and complications of the disease, and using illustrating materials (drawings, leaflets, electronic material, etc.) are strong determinants of successful medical education among caregivers, which was defined as good understanding of the nature and effects of the child's disease and alleviation of anxiety. We propose that medical education should be classified according to the aims into three categories, including education for psychosocial issues, education for clinical and follow-up care issues, and education for scientific issues; each should be implemented in a standardized framework supported by timely and personalized counseling.

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