Quality of life for adolescent with congenital heart diseases

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Abstract

Background: Congenital heart disease is the most frequent form of major birth defect in adolescents. **Aim:** This study aims to assess quality of life for adolescent with congenital heart diseases. **Design:** A descriptive study. **Sampling:** A purposive sample comprised of 200 Adolescents diagnosed with congenital heart disease. **Setting** This study was conducted in the outpatient cardiology clinics in Academy of Heart affiliated to Ain shams University Hospitals. **Tools of data collection:** Tool I: included interviewing questionnaire, consisted of: (I) Sociodemographic data, (II) Past and present Medical history, (III) adolescent's knowledge regarding CHD, (IV) health needs of adolescents with CHD, (V) Problems of adolescents with CHD, (VI) quality of life for adolescent with CHD adopted from PedsQL™ Cardiac Module. Tool II: Medical Records review of the adolescents **Results:** This study revealed that the mean age of studied adolescents was 14.85±2.82, about sixty-six percent of them were males, about seventy percent of studied adolescents had satisfactory knowledge about congenital heart disease. About fifty-seven percent of studied adolescents have moderate health problems, and fifty-four percent of them have moderate QOL. **Conclusion**: Upon the findings of the current study, the studied adolescents had possible needs related to congenital heart disease, also had moderate health problems and moderate total quality of life, which is being affected by their sociodemographic data, their knowledge about the disease, their health needs. There is positive relation between the adolescents' health Problems and their quality of life. Also, there is positive relation between the adolescents' socio-demographic data (Age, educational level, residence and financial income) and their knowledge about the congenital heart disease. **Recommendation:** continuous education for all adolescents with CHD about their disease, how to improve their quality of life and about their needs. Further detailed studies about adolescents with congenital heart disease and their knowledge, needs, problems and quality of life.

Keywords: adolescent - Quality of life -congenital heart disease - CHD.

Introduction:

Congenital heart disease (CHD) is one or more problems with the heart's structure that exist since birth. Congenital means that you're born with the defect. Congenital heart disease, also called congenital heart defect, can change the way blood flows through your heart. Some congenital heart defects might not cause any problems. Complex defects, however, can cause life-threatening complications **(Zaidi S & Brueckner M 2019).**

Congenital Heart Disease are primarily structural alterations that erase due to errors in embryological development of the heart and great vessels. These resulting abnormalities range in severity from miniscule holes between chambers that may subsequently close to complex malformations that will require multiple surgical corrections to allow the affected patient to survive **(Amedro et al., 2018).**

Improved surgical care, together

with the advances in medical management, have led to a remarkable increase in survival of patients with CHD. Accordingly, in some developed countries, the number of adults now exceeds the number of children with CHD, and, as these patients mature into adulthood, many develop late cardiac complications. Despite these facts, in some parts of the world there is little information about this group of patients and their needs. Specifically, in Egypt, data on the clinical profile of adult patients with CHD is lacking **(Mayo Clinic, 2015).**

W.H.O describes 'Adolescents' as people in the 10-19 years old age category and. Adolescents are not a similar population. They exist in various conditions and have changed needs. The conversion from child to adult involves physical, sexual, psychological, and social progressive changes, all happening together. In addition to opportunities for development this transition poses risks to their health and well-being **(WHO, 2016)**

Community Nurses caring for Adolescents with CHD are uniquely skilled at educating families about the importance of health maintenance needs. Nurses must partner with parents in order to develop an individualized health maintenance and promotion plan that will address the child's physical, developmental, psychosocial, and cognitive needs as well as foster parental well-being and appropriate coping mechanisms **(Banar, 2014).**

Patients with CHD face challenges in relation to sociological and disease-specific factors as well as in terms of the health services they require. In the sociological domain, they can have life experiences of disease, poverty, powerlessness, and racism. The disease-specific domain comes from the fact that these patients have insufficient access to primary healthcare and lack information about their condition. Finally, patients with rheumatic heart disease often experience a lack of health communication and a positive experience is emphasized in the challenges of the health service domain **(Haynes et al., 2020).**

Significance of the study:

Congenital heart disease (CHD) is the most common category of congenital defects, with a prevalence of 8 to 10 per 1,000 live births. Adolescents' mortality related to CHD decreased by 31% between 1987 and 2005. This survival trend is predicted to increase each year due to advancements in treatment and management of CHD. This significant shift in the epidemiology of CHD requires nurses to take action in preparing adolescents with CHD and their families for their teenage years and young adulthood. Adolescents with CHD has specific physical, intellectual, emotional, and developmental needs that must be considered and managed using a multidisciplinary approach **(Khairy et al., 2010).**

Adolescents with many types of CHD are living beyond the expectations. Advances in cardiac surgery, cardiac catheterization, interventional cardiology, noninvasive imaging, early diagnosis with fetal assessment, and complex critical nursing care have led to 85% to 90% of adolescents with CHD reaching adulthood. Unfortunately, some families do not appreciate the need for long-term follow-up and care, believing instead that their adolescent's repair or stable cardiovascular status deems the visits unnecessary **(Gurvitz et al., 2013)**.

Aim of the study:

This study aims to Assess Quality of life for adolescent with congenital heart diseases through:

• Assessing knowledge of adolescents

about congenital heart diseases.
• Assessing health needs of adolescents with congenital heart diseases.
• Assessing health problems of adolescents with congenital heart diseases.
• Assessing physical, social and psychological aspects of quality of life for adolescent with congenital heart diseases.

Research Questions:
• What are health needs of adolescents with congenital heart diseases?
• What are health problems of adolescents with congenital heart diseases?
• What is the quality of life of adolescents with congenital heart disease?
• Is there a relation between health problems of adolescents with congenital heart diseases and their quality of life?
• Is there a relation between adolescents' socio demographic characteristics and their knowledge about congenital heart diseases?

Subjects and Method:
I. Technical design:
Research Design:

A descriptive research design was selected to fulfill the aim of the study and answer the research question.

Research Setting:

This study was conducted in the outpatient cardiology clinics in Academy of Heart affiliated to Ain shams University Hospitals as it is the main cardiology hospital which receives patients from all Egypt.

Subjects of study:

The number of adolescents with congenital heart disease in the mentioned setting in (2019) was 465. A purposive sample "200 adolescents" was used in this study according to the following formula.

• CL= Confidence Level: 95%
• N= Population Size: 465
• e= Margin of Error: 5% (0.05)
• P= Standard deviation: 0.5
• Z= Z Score (For CL:95%): 1.96
• Sample Size = 200

$$Sample\ Size = \cfrac{\dfrac{Z^2 \times P(1-P)}{e^2}}{1 + \dfrac{Z^2 \times P(1-P)}{e^2 \times N}}$$

Inclusion Criteria:

• Adolescents diagnosed with congenital heart disease.
• Age ranged between 10 years and 19 years.
• Adolescents who are receiving all types of treatment (medical, surgical, interventional).

Tools of data collection:

Two tools were used for data collection:

1st tool: Interviewing questionnaire sheet:

It was designed by the investigator in an Arabic language after reviewing the recent and related literatures and it consists of six parts:

Part I: Socio-Demographic characteristics of adolescents diagnosed with congenital heart disease (age, Gender, level of education, marital status, Occupation, residence, Income, family members and housing). (**10 questions: Q1-Q10**)

❖ **Scoring System of household**

crowding rate:

The household crowding index (HCI) was defined as the total number of co-residents per household divided by the total number of rooms, excluding the kitchen and bathrooms. The continuous variable was re-grouped into two distinct categories:

(1) 0-2 residents per room. "Low crowd rate"
(2) >2 residents per room. "High crowd rate"

Part II: past and present medical history of the adolescents. This part was designed by the investigator to assess past and present medical history of the studied sample (Chronic disease, hospitalization, past surgeries, Smoking, current medical diagnosis, medical investigations, treatment received, follow up place and follow up scheduling) (**11 questions: Q11-Q21**).

Part III: adolescent's knowledge regarding congenital heart diseases. This part was designed by the investigator to assess adolescent's knowledge regarding congenital heart diseases (Meaning, causes, sign, symptoms, special diet, diagnosis, complication, Treatment, and lifestyle) (**12 questions: Q22-Q33**).

❖ **Scoring System of knowledge:**

The answers were checked with a model key answer that prepared by the investigator. The scoring system was designed with rating ranging from 0 (Incorrect) to 1 (Correct) point for each item. Each question response was either Incorrect (0 grade) and Correct (1 grade).

Score % = (the observed score / the maximum score) × 100

The total score was from 0-15 grades:

• Satisfactory Knowledge **(>50%)**
• Unsatisfactory Knowledge **(0% - 50%)**

Part IV: Health needs of adolescents with congenital heart diseases. This part was adopted by the investigator from "***Child and adolescent needs and strengths (CANS) manual: The NCTSN CANS comprehensive Version A Comprehensive Information Integration Tool for Children and Adolescents, August 2016***" to assess health needs of adolescents with congenital heart diseases among the studied sample with three degrees (never, sometimes, and always). (**24 questions: Q34-Q57**)

❖ **Scoring System of measuring adolescent needs:**

The scoring system was adopted with rating ranging from 0 (Always) to 2 (Never) point for each item. Each question response was either Always "**No evidence of need**" (0 grade), Sometimes "**Significant history or possible need**" (1 grade) and Never "**Significant need**" (2 grade).

Score % = (the observed score / the maximum score) × 100

The total score was from 0-48 grades:

• No evidence of needs - No action needed **(< 50%).**
• Possible needs - follow up and preventive action are recommended **(50% -75%).**
• Significant Needs - intensive action required **(>75%).**

Part V: health problems of adolescents with congenital heart diseases. This part was designed by the investigator to assess health problems of adolescents

with congenital heart diseases among the studied sample with three degrees (Mild, Moderate, and Sever). (**18 questions: Q58-Q75**)

❖ **Scoring System of health problems**

The scoring system was adopted with rating ranging from 0 to 2 points for each item. Each question response was either never (0 grade), sometimes (1 grade) and always (2 grade).

Score % = (the observed score / the maximum score) × 100

The total score was from 0-36 grades:

- Mild problems **(<50%)**
- Moderate problems **(50-75%)**
- Severe problems **(>75%)**

Part VI: Quality of life for adolescents with congenital heart disease questionnaire for assessing aspects of quality of life for adolescent with congenital heart diseases (physical, social, psychological) this tool was adopted from *(PedsQL™ Cardiac Module, JW Vami, Version 17, May 2017)* (**34 questions: Q76-Q109**)

❖ **Scoring System of Quality of life:**

The scoring system was adopted with rating ranging from 0 to 2 points for each item. Each question response was either never (0 grade), sometimes (1 grade) and always (2 grade).

Score % = (the observed score / the maximum score) × 100

The total score was from 0-68 grades:

- Poor QOL (**<50%**)
- Moderate QOL **(50-75%)**
- Good QOL **(>75%)**

2nd tool: Medical Records review of the adolescents which include diagnosis, when the disease started, the time of the treatment initiation and evaluate physical, circulatory, respiratory, urinary tract, nervous, motor system and skin condition for the adolescent and include the results of laboratory investigations.

Operational design:
The operational design of this study included preparatory phase, validity and reliability of the developed tools, pilot study, field work, and ethical consideration.

Preparatory phase:

It included reviewing the recent and related literatures covering various aspects of the study problem using books, articles, internet, periodicals and magazines in order to develop tools for data collection.

Validity:

The tools were tested and evaluated for their face and content validity. Face and content validity are tested by five experts in Public Nursing department in Faculty of Nursing Ain Shams University, to ascertain relevance, clarity and completeness of the tools. The developed tools were modified according to the experts' opinion; these modifications were in the form of omission or addition of some questions or rephrasing of some statements.

Reliability:

The internal consistency was measured to identify the extent to which the items of **tool I** measure the same

concepts and correlate with each other by using Alpha Cronbach's test. For reliability test-retest was done (0.84).

Pilot study:

The pilot study was conducted on 20 adolescents (10% of total sample), to ensure the clarity of questions, applicability of the tools and the time needed to fill the questionnaires. No modifications were done after pilot study and those adolescents were included in the actual study sample.

Ethical consideration:

Ethical approval was obtained from the scientific ethical committee of faculty of nursing, Ain Shams University. In addition, written consent was obtained from every participant who agreed to share in the study. They were assured that anonymity and confidentiality were guaranteed and the right to withdraw from the study at any time. Ethics, values, culture and beliefs were respected.

Field work:

The actual field work of the process of data collection was done in a period of six months; started from the beginning of July 2019 till the end of Jan 2020, data were collected at each study setting. The researcher explained the aim of the study to each patient. The researcher interviewed individually the patients who agreed to participate in the study. The study tools were filled by the researcher and took about 30-45 minutes for each patient.

III.   Administrative design:

An official approval was obtained to carry out the study that issued from the Dean of Faculty of Nursing, Ain Shams University to the Directors of Academy of Heart affiliated to Ain shams University Hospitals.

IV.Statistical design:

The collected data were organized, coded and analyzed by using appropriate statistically significant tests. Recorded data were analyzed using the statistical package for social sciences, version 20.0 (SPSS Inc., Chicago, Illinois, USA). Quantitative data were expressed as mean± standard deviation (SD). Qualitative data were expressed as frequency and percentage.

The following tests were done:

- Chi-square (x2) test of significance was used in order to compare proportions between qualitative parameters.
- Pearson's correlation coefficient (r) test was used to assess the degree of association between two sets of variables
- The confidence interval was set to 95% and the margin of error accepted was set to 5%. So, the p-value was considered significant as the following
- Probability (P-value)
– P-value <0.05 was considered significant.
– P-value <0.001 was considered as highly significant.
– P-value   >0.05   was   considered insignificant.

Results:

Table (1): shows that the mean age of the studied adolescents with congenital heart disease was 14.85, regarding gender 66.5% of them were male, regarding educational level 27% of them were In preparatory school, regarding marital status 88% of them were single, regarding occupational status 85% of them don't work, regarding residence 54% of them were from rural areas, regarding financial income 57.5% of them have adequate income, regarding number of family members 72.5% of them have 5-6, regarding number of rooms 48.5% of them

have three rooms, as well as crowed rate 55% of them were have low crowd rate.

Table (2): shows that there was chronic disease 21.5% of them have coronary heart disease, regarding hospitalization 88% of them were previously hospitalized, regarding cause of hospitalization 24.5% of them were for surgery, regarding surgical intervention 24.5% of them had surgical intervention, regarding surgeries 15.5% of them had tonsillectomy, as well as smoking 18% of them were smokers.

Table (3): shows that there was current medical diagnosis 15.5% of them have Atrioventricular septal defect, regarding medical investigations 90% of them had echo, regarding treatment 42% of them were on medication only, regarding follow up place 67% are going to public hospital, regarding follow up scheduling 64% of them are going for follow up according to doctor orders.

Figure (1): Showed that 62%, of adolescents with congenital heart disease had satisfactory knowledge regarding to disease nature, and 70.5% of adolescents with congenital heart disease had satisfactory knowledge regarding to lifestyle

Figure (2): shows that 69.6% of the adolescents had a satisfied level of knowledge regarding congenital heart disease and 30.5% of them had an unsatisfied level of knowledge.

Figure (3): shows that there were physical needs 60.5% of them were "possible needs", regarding personal hygiene 50.5% of them were "possible needs", regarding psychological needs 63% of them were "possible needs", regarding self-perception 57.5% of them were "possible needs", as well as home and family relationship 53.5% of them

were "possible needs".

Figure (4): shows that 30% of the adolescents had No evidence of needs regarding congenital heart disease, 61% possible needs and 9% of them had Significant needs.

Figure (5): shows that there were physical problems 54% of them were moderate, regarding psychological problems 65% of them were moderate, as well as social problems 49.5% of them were mild.

Figure (6): shows that 39.5% of the adolescents had mild health problems because of congenital heart disease, 57.5% had moderate health problems and 3% of them had severe health problems.

Figure (7): Regarding physical QOL 63.5% of studied sample were moderate, regarding social QOL 56.5% of them were moderate, as well as Psychological QOL 62% of them were moderate.

Figure (8): shows that 9% of the adolescents had poor QOL because of congenital heart disease, 54.5% had Moderate QOL and 36.5% of them had good QOL.

Table (4): presented that, there were highly statistically significant Relation between level of knowledge of the adolescents with congenital heart disease and their Educational level and Financial income at (p-value <0.001). Also, there were statistically significant Relation with their Age (years) and Occupational status (P<0.05). While, there were no significant Relation with Gender, Marital status, Occupational status and Crowd rate at (P>0.05).

Table (5): presented that, there were highly statistically significant

Relation between level of quality of life of the adolescents with congenital heart disease and their Age (years), Educational level, Financial income and Crowd rate at (p-value <0.001). Also, there were statistically significant Relation with their Occupational status (P<0.05).

Table (6): presented that, there were highly statistically significant Relation between level of knowledge and level of health needs of the adolescents with congenital heart disease. In unsatisfied knowledge, average needs increased representing 43/61 (70.5%) compared to satisfied 79/139 (56.8%), with (p-value <0.001).

Table (7): presented that, there were highly statistically significant Relation between level of knowledge and level of health problems of the adolescents with congenital heart disease. In unsatisfied knowledge, severe problems increased representing 6/61 (9.8%) compared to satisfied 0/139 (0%), with (p-value <0.001).

Table (8): presented that, there were highly statistically significant Relation between level of knowledge and level of quality of life of the adolescents with congenital heart disease. In unsatisfied knowledge, High quality of life decreased representing 6/61 (9.8%) compared to satisfied 67/139 (48.2%), with (p-value <0.001).

Table (9): presented that, there were highly statistically significant Relation between level of health needs and level of quality of life of the adolescents with congenital heart disease, there was Relation between health needs, average needs represent 67% in cases with average QoL, followed by 0% low needs in cases with low QoL and 0% high needs in cases with high QoL. with (p-value <0.001).

Table (10): presented that, there were highly statistically significant Relation between level of health problems and level of quality of life of the adolescents with congenital heart disease, there was Relation between health problems, moderate problems represent 72.5% in cases with average QoL, followed by 0% mild problems in cases with low QoL and 0% severe problems in cases with high QoL. with (p-value <0.001).

Table (11): presented that, there were highly statistically significant Relation between level of health needs and level of health problems of the adolescents with congenital heart disease, there was Relation between health needs, low needs represent 70% in cases with mild problems, followed by 69.7% average needs in cases with moderate problems and 33.3% high needs in cases with severe problems: with (p-value <0.001).

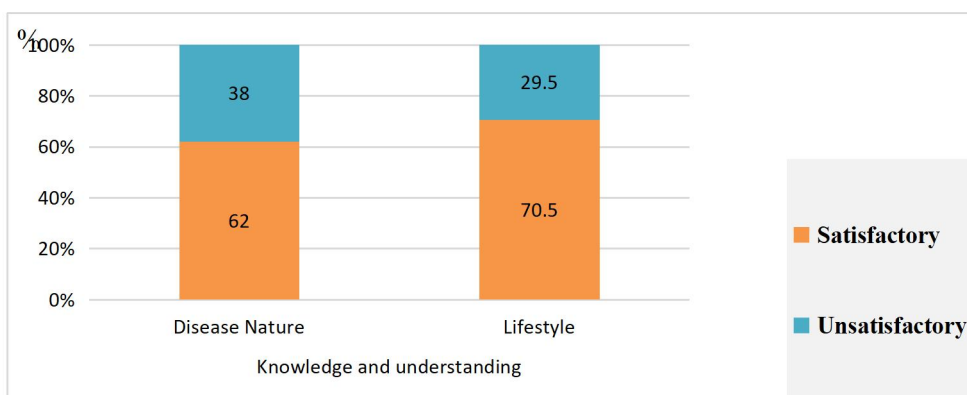**Table (1):** Distribution of adolescents with CHD according to their socio-demographic data (N=200).

Socio-demographic data	No.	%
Age (years)		
10 - <13 years	73	36.5
13 - <16 years	30	15.0
16 - 19 years	97	48.5
Mean ± SD	14.85±2.82	
Gender		
Male	133	66.5
Female	67	33.5
Educational level		
Primary school	49	24.5
Preparatory school	54	27.0
Secondary school	55	27.5
University	42	21.0
Marital status		
Single	176	88.0
Married	24	12.0
Occupational status		
Work	30	15.0
Don't work	170	85.0
Residence		
Rural	108	54.0
Urban	92	46.0
Financial income of Family		
Adequate	115	57.5
Not Adequate	85	42.5
Number of family Members		
3-4	31	15.5
5-6	145	72.5
7-8	24	12.0
Number of rooms		
2	91	45.5
3	97	48.5
4-5	12	6.0
Crowding index:		
Not crowded	110	55.0
Crowded	90	45.0

Table (2): Distribution of adolescents with CHD according to their past medical history (N=200).

Past Medical history	No.	%
Chronic disease:		
None	127	63.5
Diabetes	6	3.0
Hypertension	18	9.0
Coronary heart disease	43	21.5
Asthma	4	2.0
Renal Failure	2	1.0
Hospitalization:		
Yes	176	88.0
No	24	12.0
Cause of hospitalization: (N=176)		
Unstable angina	6	3.4
heart rhythm disorder	24	13.6
Chest pain	12	6.8
Shortness of breath	37	21.0
Surgery	49	27.8
Abdominal pain	29	16.5
Fever	15	8.5
Hypoglycemia	4	2.3
Surgical intervention		
Yes	49	24.5
No	151	75.5
Surgeries: (N=49)		
Cholecystectomy	12	24.5
Tonsillectomy	31	63.3
Caesarean section	6	12.2
Smoking:		
Yes	36	18.0
No	164	82.0

Table (3): Number and percentage distribution of adolescents with CHD according to their present medical history (N=200).

Current Medical history	No.	%
Current medical diagnosis:		
Ventricular septal defect	25	**12.5**
Coarctation of the aorta	13	**6.5**
Pulmonary valve stenosis	29	**14.5**
Aortic valve stenosis	17	**8.5**
Tetralogy of Fallot	12	**6.0**
Atrial septal defect	13	**6.5**
Mitral valve regurgitation	24	**12.0**
Aortic valve regurgitation	25	**12.5**
Atrioventricular septal defect	31	**15.5**
Pulmonary atresia	4	**2.0**
Hypoplastic right heart syndrome	7	**3.5**
* Medical Investigations:		
ECG	162	**81.0**
Echo	180	**90.0**
Stress ECG	42	**21.0**
Stress Echo	48	**24.0**
Diagnostic angiography	42	**21.0**
Atomic scanning	24	**12.0**
CT	48	**24.0**
Labs	108	**54.0**
Treatment:		
Surgery	37	**18.5**
Medications	84	**42.0**
Catheterization intervention	79	**39.5**
Follow up place:		
Public hospital	134	**67.0**
Private hospital/doctor	66	**33.0**
Follow up scheduling:		
Regular visits	36	**18.0**
According to Doctor orders	128	**64.0**
On sickness feeling	36	**18.0**

Fig. (1): Percentage distribution of adolescents with CHD according to their total knowledge about CHD. (N=200).
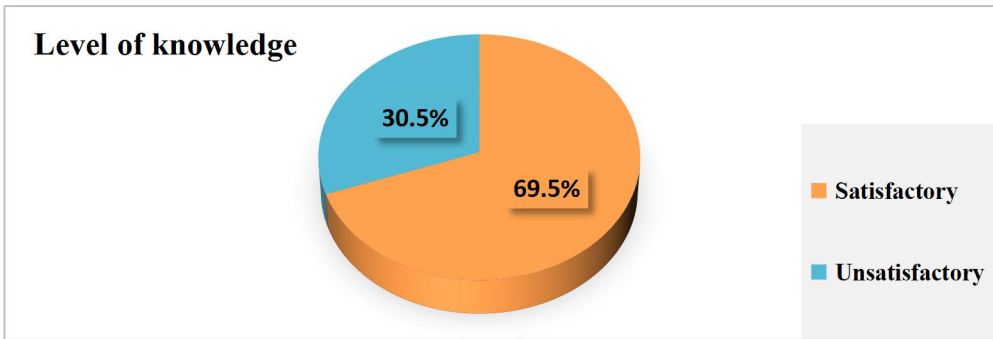
Level of knowledge

30.5%

69.5%

■ Satisfactory

■ Unsatisfactory

Fig. (2): Percentage distribution of adolescents with CHD according to their total knowledge about CHD. (N=200).

%100%   6.5   13.5   23.5   5

80%   60.5   63   57.5   53.5

60%

40%   33   23.5   19   41.5

20%

0%   Physical   Psychological Self-   Home and
        needs   needs   perception Family
                                          relationship

■ Significant need

■ possible need

■ No evidence of need

Health needs

Fig. (3): Percentage distribution of adolescents with CHD according to their total health needs. (N=200).

Level of health needs

9.0%   30.0%

61.0%

■ No evidence of needs

■ possible needs
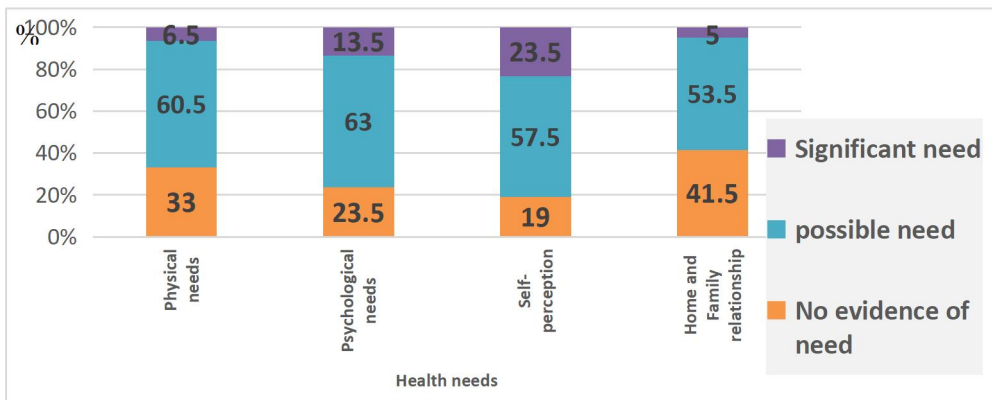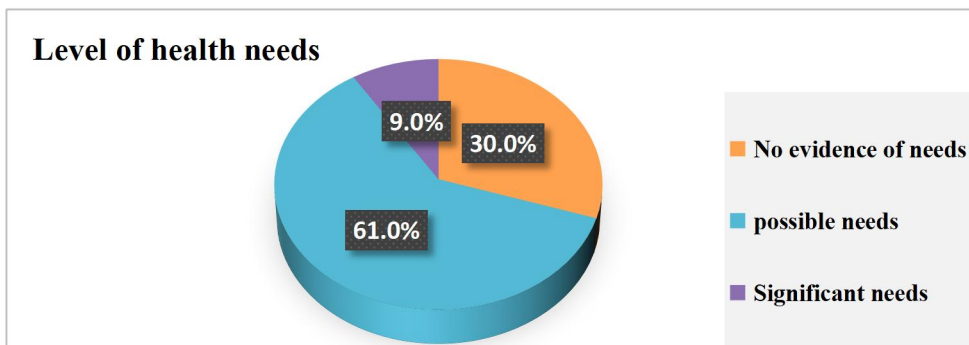
■ Significant needs

Fig. (4): Percentage distribution of adolescents with CHD according to their total health needs (N=200).
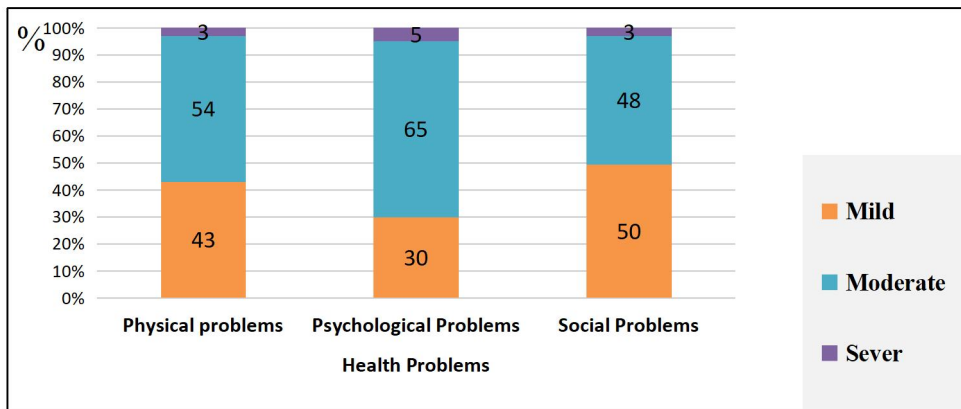
Fig. (5): Percentage distribution of adolescents with CHD according to their total health problems. (N=200).
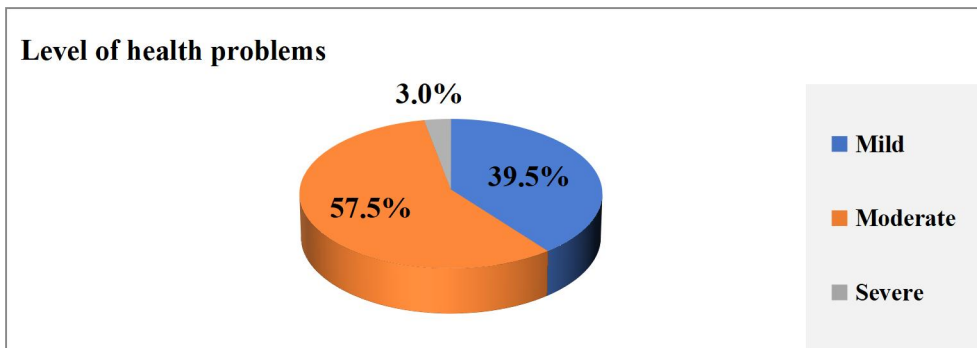

Fig. (6): Percentage distribution of adolescents with CHD according to their total health problems (N=200).
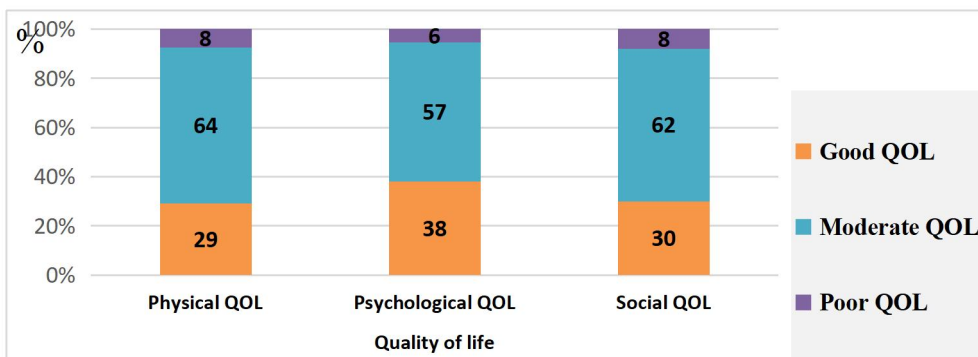

Fig. (7): Percentage distribution of adolescents with CHD according to their total quality of life (N=200).
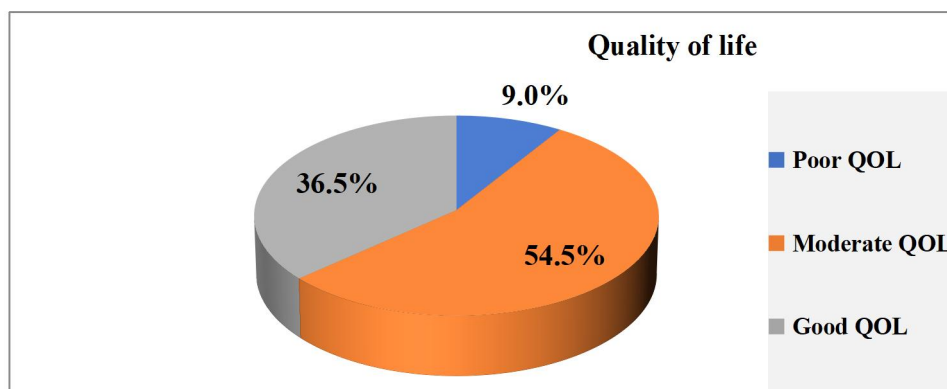
Fig. (8): Percentage distribution of adolescents with CHD according to their total quality of life

Table (4): Relation between level of knowledge of the adolescents with CHD and their socio-demographic data (n=200).

Socio-demographic data	Level of knowledge				Chi-square test	
	Satisfied (n=139)		Unsatisfied (n=61)			
	No.	%	No.	%	x2	p-value
Age (years)						
10 to 12	44	**31.7%**	29	**47.5%**		
13 to 15	18	**12.9%**	12	**19.7%**	**8.677**	**0.013***
16 to 19	77	**55.4%**	20	**32.8%**		
Gender						
Female	46	**33.1%**	21	**34.4%**	**0.003**	**0.956**
Male	93	**66.9%**	40	**65.6%**		
Educational level						
In preparatory school	42	**30.2%**	12	**19.7%**		
In primary school	36	**25.9%**	13	**21.3%**	**29.664**	**<0.001****
In secondary school	31	**22.3%**	24	**36.6%**		
In university	30	**21.6%**	12	**19.7%**		
Marital status						
Married	16	**11.5%**	8	**13.1%**	**0.007**	**0.932**
Single	123	**88.5%**	53	**86.9%**		
Occupational status						
Don't work	121	**87.1%**	49	**80.3%**	**1.022**	**0.312**
Work	18	**12.9%**	12	**19.7%**		
Residence						
Rural	68	**48.9%**	40	**65.6%**	**4.086**	**0.043***
Urban	71	**51.1%**	21	**34.4%**		
Financial income						
Adequate	95	**68.3%**	20	**32.8%**	**20.504**	**<0.001****
Not Adequate	44	**31.7%**	41	**67.2%**		
Crowd rate:						
High	66	**47.5%**	24	**39.3%**	**1.134**	**0.287**
Low	73	**52.5%**	37	**60.7%**		

Using: Chi-square test; p-value >0.05 NS; *p-value <0.05 S; **p-value <0.001 HS

Table (5): Relation between level of quality of life of the adolescents with CHD and their socio-demographic data (n=200).

Socio-demographic data	Quality of life						Chi-square test	
	Low (n=18)		Average (n=109)		High (n=73)			
	No.	%	No.	%	No.	%	x2	p-value
Age (years)								
10 to 12	18	100.0%	37	33.9%	18	24.7%		
13 to 15	0	0.0%	24	22.0%	6	8.2%	45.800	<0.001**
16 to 19	0	0.0%	48	44.0%	49	67.1%		
Gender								
Female	8	44.4%	36	33.0%	23	31.5%	1.109	0.574
Male	10	55.6%	73	67.0%	50	68.5%		
Educational level								
In preparatory school	2	11.1%	29	26.6%	23	31.5%		
In primary school	6	33.3%	21	19.3%	22	30.1%	39.166	<0.001**
In secondary school	0	0.0%	31	28.4%	24	32.9%		
In university	10	55.6%	28	25.7%	4	5.5%		
Marital status								
Married	0	0.0%	18	16.5%	6	8.2%	5.546	0.062
Single	18	100.0%	91	83.5%	67	91.8%		
Occupational status								
Don't work	18	100.0%	97	89.0%	55	75.3%	9.878	0.007*
Work	0	0.0%	12	11.0%	18	24.7%		
Residence								
Rural	12	66.7%	54	49.5%	42	57.5%	2.402	0.301
Urban	6	33.3%	55	50.5%	31	42.5%		
Financial income								
Adequate	18	100.0%	48	44.0%	49	67.1%	24.156	<0.001*
Not Adequate	0	0.0%	61	56.0%	24	32.9%		
Crowd rate:								
High	18	100.0%	54	49.5%	18	24.7%	35.114	<0.001**
Low	0	0.0%	55	50.5%	55	75.3%		

Using: Chi-square test; p-value >0.05 NS; *p-value <0.05 S; **p-value <0.001 HS

Table (6): Relation between level of knowledge of the adolescents with CHD and their level of health needs (n=200).

Level of health needs	Level of knowledge				Total		Chi-square test	
	Satisfied		Unsatisfied					
	No.	%	No.	%	No.	%	x2	p-value
Low	53	34.5%	7	19.7%	60	30.0%		
Average	79	56.8%	43	70.5%	122	61.0%	19.293	<0.001**
High	7	8.6%	11	9.8%	18	9.0%		
Total	139	100.0%	61	100.0%	200	100.0%		

Chi-square test; **p-value <0.001 HS

Table (7): Relation between level of knowledge of the adolescents with CHD and their level of health problems (n=200).

Level of health problems	Level of knowledge				Total		Chi-square test	
	Satisfied		Unsatisfied					
	No.	%	No.	%	No.	%	x2	p-value
Mild	61	43.9%	18	29.5%	79	39.5%		
Moderate	78	56.1%	37	60.7%	115	57.5%	**16.043**	**<0.001**
Severe	0	0.0%	6	9.8%	6	3.0%		
Total	139	100.0%	61	100.0%	200	100.0%		

Chi-square test; **p-value <0.001 HS

Table (8): Relation between level of knowledge of the adolescents with CHD and their level of quality of life (n=200).

Quality of life	Level of knowledge				Total		Chi-square test	
	Satisfied		Unsatisfied					
	No.	%	No.	%	No.	%	x2	p-value
Low	18	12.9%	0	0.0%	18	9.0%		
Average	54	38.8%	55	90.2%	109	54.5%	45.479	**<0.001**
High	67	48.2%	6	9.8%	73	36.5%		
Total	139	100.0%	61	100.0%	200	100.0%		

Chi-square test; **p-value <0.001 HS

Table (9): Relation between level of quality of life of the adolescents with CHD and their level of health needs (n=200).

Level of health needs	Quality of life						Total		Chi-square test	
	Low QOL		Average QOL		Best QOL					
	No.	%	No.	%	No.	%	No.	%	x2	p-value
Low	0	0.0%	18	16.5%	42	57.5%	60	30.0%		
Average	18	100.0%	73	67.0%	31	42.5%	122	61.0%	54.720	**<0.001**
High	0	0.0%	18	16.5%	0	0.0%	18	9.0%		
Total	18	100.0%	109	100.0%	73	100.0%	200	100.0%		

Chi-square test; **p-value <0.001 HS

Table (10): Relation between level of quality of life of the adolescents with CHD and their level of health problems (n=200).

Level of health problems	Quality of life						Total		Chi-square test	
	Low QOL		Average QOL		Best QOL					
	No.	%	No.	%	No.	%	No.	%	x2	p-value
Mild	0	0.0%	24	22.0%	55	75.3%	79	39.5%		
Moderate	18	100.0%	79	72.5%	18	24.7%	115	57.5%	67.895	**<0.001**
Severe	0	0.0%	6	5.5%	0	0.0%	6	3.0%		
Total	18	100.0%	109	100.0%	73	100.0%	200	100.0%		

Chi-square test; **p-value <0.001 HS

Table (11): Relation between level of level of health needs of the adolescents with CHD and their level of health problems (n=200).

Level of health problems	Level of health needs						Total		Chi-square test	
	Low		Average		High					
	No.	%	No.	%	No.	%	No.	%	x2	p-value
Mild	42	70.0%	37	30.3%	0	0.0%	79	39.5%		
Moderate	18	30.0%	85	69.7%	12	66.7%	115	57.5%	34.453	<0.001**
Severe	0	0.0%	0	0.0%	6	33.3%	6	3.0%		
Total	60	100.0%	122	100.0%	18	100.0%	200	100.0%		

Chi-square test; **p-value <0.001 HS

Discussion

Abnormalities of the heart or the blood vessels, formed during fetal life (3 to 6 weeks of pregnancy), i.e. when the heart or the major blood vessels of the heart can't develop properly before birth. The abnormalities involving the arteries, the valves, the coronary and the major vessels of the heart can be either simple or complex. *(Brennan, 2017)*

Quality of life reflects the patient's perception of the impact of the illness and its treatment on their life. Though considerable advances were made during last decades in applying measurement of quality of life in daily clinical practice, only until recently its' assessment has been progressively acknowledged as an essential health outcome measure in clinical trials and health services research and evaluation. Moreover, it reflects an option for recognizing adolescents that need support due to the severe difficulties they experience. *(Schlarmann,2018)*

Improved surgical care, together with the advances in medical management, have led to a remarkable increase in survival of patients with CHD. Accordingly, in some developed countries, the number of adults now exceeds the number of children with CHD, and, as these patients mature into adulthood,

many develop late cardiac complications. Despite these facts, in some parts of the world there is little information about this group of patients and their needs. Specifically, in Egypt, data on the clinical profile of adult patients with CHD is lacking. *(Mayo Clinic,2015)*

Those suffering from CHD now live well past Childhood and even into adulthood as a result of technological advances in pediatric cardiology. Adulthood, thereby increasing the need for appropriate and specialized health care services for this emerging population of adolescents with CHD. These individuals are viewed as unique in the medical world and as they move forward with theirlives, their parents and health care practitioners alike face new challenges. In fact, parents must face the realization that their children are pushing for independence in all aspects of their lives and acknowledge the influence of this on their teen's heart health. *(American Heart Association, 2013)*

Part I: Socio-demographic characteristics

Regarding to characteristics of the studied adolescents, the finding of the present study showed that more than half of them were at the age between 10 and

less than 19 years with mean age 14.85±2.82 years and two thirds of them were males **(Table 1)**. This finding agrees with *Manu et al., (2019)* who carried out a study entitled "Health-related quality of life in children and adolescents with CHD: a cross-sectional survey from South India" and found that the mean age of the studied adolescents were 12.03 ± 3.14 years and more than half of them were males. Moreover, this finding was supported with *Barbara et al., (2019)* who carried out a study entitled "Quality of life in young people with CHD is better than expected" and found that the studied patients were aged between 8 and 17 years with mean 12.9±3.1 and the two thirds of them were males.

As regards the educational level, the results of the present study revealed that more than one quarter of them were in preparatory school and about quarter of them in primary school **(Table 1)**. This finding was agreed with *Yu-Mi et al., (2018)* who conducted a study entitled "Health condition and familial factors associated with health-related quality of life in adolescents with CHD: a cross sectional study in the United Kingdom." and found that half of the studied sample were in ≤ middle school. Moreover, this finding disagreed with *Amedro et al., (2016)* who conducted a study entitled "Quality of Life of Children with CHD" in France and found that half of the studied patients were in the Preparatory school. From the researcher point of view, these differences may be due to differences of the study settings.

Concerning the studied patients' residence, the finding of the present study illustrated that more than half of the patients coming from rural areas **(Table 1)**. The finding agreed with *Manu et al., (2019)* who carried out a study entitled "Health-related quality of life (HRQOL) in children and adolescents with CHD: a

cross-sectional survey from South India" and found that less than two thirds of the patients coming from rural areas. Moreover, the finding disagreed with *Barbara et al., (2019)* who conducted a study entitled "Quality of life in young people with CHD is better than expected" in Germany and found that, more than three quarters of the patients coming from rural areas. From the researcher point of view, these differences may be due to differences of the study settings.

Part II: Medical history:
As regards other chronic diseases, the present study showed that slightly about two thirds didn't have any other chronic diseases **(Table 2)**. These findings were supported by *Juliana et al., (2015)* who conducted a study entitled "Health-related quality of life in adolescents with congenital heart disease" in Brazil and found that majority of the studied sample didn't have any other chronic diseases. From the researcher's point of view the Congenital heart disease is not directly related to having other chronic diseases

Concerning the treatment, the findings of this study revealed that, more than third of the studied patients had Catheterization intervention and only less than one fifth of them had surgical intervention **(Table 3)**. This finding agrees with *Amedro et al., (2016)* who conducted a study entitled "Quality of Life of Children with CHD" in France and found that about less than half of the studied sample had Catheterization intervention for treatment and disagree with him as he found that about more than half of them had surgical intervention. From the researcher point of view, these differences may be due to differences of the study settings and sample criteria

Part III: Knowledge about CHD:
Regarding to adolescents' knowledge about disease. The present

study revealed that more than two thirds of them had satisfactory knowledge regarding congenital heart diseases from total knowledge **(Fig. 2)**. These disagree with that of ***Animasahun et al., (2015)***, who conducted a study entitled "Caregivers of Children with Congenital Heart Disease" in Nigeria and showed that more than two thirds of studied sample had unsatisfactory knowledge about congenital heart diseases. From the researcher point of view the results of present study could be attributed to the sample criteria and the time that the study was done

Part IV: Health needs for adolescents with CHD:

Regarding to adolescents' health needs. The present study revealed that more than half of them had possible health needs related to congenital heart diseases **(Fig. 4)**. These disagree with that of ***Ryberg, (2019)***, who conducted a study entitled "Children with Congenital Heart Defects" in Sweden and showed that more than half of studied sample had significant health needs related to congenital heart diseases. From the researcher point of view the results of present study could be attributed to the sample criteria and the setting the study was performed in.

Part V: Health problems for adolescents with CHD:

Regarding the health problems for adolescents with congenital heart diseases, the current study revealed that more than half of studied sample had Moderate health problems **(Fig. 6)**. These findings agreed with those of ***Eur, (2017)***, who conducted a study entitled "Adolescents with congenital heart disease: their opinions about the preparation for transfer to adult care" in Sweden and reported that the majority of studied sample had moderate health problems in all domains.

Part VI: Quality of life:

Regarding the total quality of life for adolescents with congenital heart diseases, the current study revealed that more than half of studied sample had Moderate quality of life (**Figure 8**). These findings agreed with those of ***Ladak et al (2018)*** who conducted a study entitled "Health-related quality of life in surgical children and adolescents with congenital heart disease compared with their age-matched healthy sibling" in Pakistan and reported that the majority of studied sample had moderate health related quality of life in all domains.

Part VII: Relations between different domains:

In Table (4) The current study showed that that, there were highly statistically significant Relation between level of knowledge of the adolescents with congenital heart disease and their Educational level at (p-value <0.001). This result was similar with that of ***Noori, (2017)***, who conducted a study entitled "Quality of Life in Children and Adolescents with Congenital Heart Diseases in Zahedan, Iran" and denoted that the patients graduated from high school or studying in university thought that they had better Knowledge than those graduated from primary and/or secondary schools.

In Table (4) The current study showed that there were highly statistically significant Relation between level of knowledge of the adolescents with congenital heart disease and their income at (p-value <0.001**). This result was similar with that of ***Noori, (2017)***, who conducted a study entitled "Quality of Life in Children and Adolescents with Congenital Heart Diseases in Zahedan, Iran" and denoted that the adolescents who have higher monthly income had better Knowledge than those who have

lower monthly income.

In **Table (4)** The finding of the present study presented that, there were statistically significant Relation between level of knowledge of the adolescents with congenital heart disease and their Age (years) at (p-value <0.013*). This result was similar with that of *Amedro, (2018)*, who conducted a study entitled "Cardiopulmonary fitness in children with congenital heart diseases versus healthy children" in France and denoted that the older adolescents had better Knowledge than the younger ones.

In **Table (5)** The finding of the present study presented that, there were statistically significant Relation between total quality of life and their monthly income at (p-value <0.001**). This result was similar with that of *Abassi, et al., (2020)*, who conducted a study entitled "Health-related quality of life in children with congenital heart disease aged 5 to 7 years" in France and denoted that who have higher monthly income had less problems than those who have lower monthly income.

In **Table (6)** The current study showed that, there were statistically significant Relation between total level of knowledge of Adolescents with congenital heart disease and their health needs at (p-value <0.001**). This result was similar with that of *Magalie et al., (2018)*, who conducted a study entitled "Educational needs of adolescents with congenital heart disease: Impact of a transition intervention program" in France and denoted that there is significant relation between the adolescents' knowledge about congenital heart disease and their health needs.

In **Table (7)** The current study showed that, there were statistically significant Relation between total level of knowledge of Adolescents with congenital

heart disease and their health problems at (p-value <0.001**). This result was similar with that of *Astrid et al., (2017)*, who conducted a study entitled "Exploring the relationship between disease-related knowledge and health risk behaviors in young people with congenital heart disease" in Belgium and denoted that there is significant relation between the adolescents' knowledge about CHD and their health problems.

In **Table (8)** The current study showed that there was statistically significant relation between their total quality of life and their total knowledge regarding CHDs (p-value = <0.001**). This result was consistent with that of *Abdel Salam & Mahmoud (2018)*, who conducted a study entitled "Effect of Educational Program on the Self- Efficacy and quality of life for mothers caring children with congenital heart disease at Benha University Hospital" and revealed that there was statistically significant relation between their total knowledge and their total quality of life regarding CHDs (p-value = 0.005*). This finding disagreed with finding of *Abdel Wanis, (2014)*, who conducted a study entitled "Quality of life for school age children with type I diabetes" in Cairo and reported that that there was no statistically significant deference between their total QOL and their total knowledge regarding CHD.

In **Table (9)** The current study showed that there were highly statistically significant Relation between level of health needs and level of quality of life of the adolescents with congenital heart disease (p-value <0.001). This result agreed with that of C*hen, (2017)*, who conducted a study entitled "Healthcare needs of adolescents with CHD transitioning into adulthood" in Taiwan and denoted that there were highly statistically significant Relation between level of health needs and level of quality

of life of the adolescents with congenital heart disease

In **Table (10)** The finding of the present study presented that, there were highly statistically significant Relation between level of health problems and level of quality of life of the adolescents with congenital heart disease (p-value = 0.001**). This result was similar with that of *Noori, (2017)*, who conducted a study entitled "Quality of Life in Children and Adolescents with CHD in Zahedan, Iran" denoted that there was highly statistically significant relation between level of health problems and level of quality of life of the adolescents with CHD.

In **Table (11)** The current study showed that there were highly statistically significant Relation between level of health problems and level of health needs of the adolescents with congenital heart disease with (p-value <0.001**). This result agreed with that of *Albasheri. (2017)*, who conducted a study entitled "Life Quality of Children with Congenital Heart Disease" in Saudi Arabia and denoted that the severity of CHD related health problems significantly affects the level of health needs

Conclusion

The present study concluded that the mean Age of the studied sample was 14.85 ± 2.82 year, and the most common congenital heart disease is atrioventricular septal defect. Most of the studied adolescents had possible self-perception and psychological needs, also the psychological problems were seen to be the most common health problems for the adolescents with congenital heart disease. The current study also clarified that most of the studied adolescents had moderate total quality of life. The present study also showed that there is highly significant relation between the adolescents' health

Problems and their quality of life as well as there is highly significant relation between the adolescents' socio-demographic data and their knowledge about the congenital heart disease

Recommendation:

1. Education program to raise health awareness for all adolescents with congenital heart disease about their disease and how to improve their quality of life.
2. Provide continuous health education to the adolescents about their needs and problems as it will differ from age to other
3. Further studies about adolescents with congenital heart disease and their knowledge, needs, problems and quality of life I had a vision

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