



Original Article

Quality of Life Among Children With Congenital Heart Defect Based on Parents' Proxy-Report

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ABSTRACT

Background: The aims of this study was to evaluate quality of life among children with congenital heart defect (CHD) and to determine the associated factors based on parents' proxy-reports.

Methods: This cross-sectional study was conducted on 263 children with CHD using inventory of PedsQoL 3.0. The PedsQoL 3.0 scores reported by parents of children. The association between quality of life and patients characteristics were assessed using multivariate linear regression method.

Results: The mean score of total quality of life was 51.6 (SD = 9.68). Re-hospitalization cost was high for the majority of families (46.8%). Heart problem scale of quality of life was significantly associated with mothers' education and age. On treatment scale, only age had significant correlation. Physical appearances, was associate with number of household and type of diseases. Anxiety was significantly associated with age and re-hospitalization status. Cognition correlated with household numbers and age. Total quality of life was significantly associated with income, age and number of household.

Conclusion: The study found some important predictors of quality of life in children with CHD. The results can be used for further educational and supportive programs for these patients.

Keywords: Children, Congenital Heart Defects, Quality of life

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Introduction

Congenital heart diseases (CHDs) are the second cause of death in children with an occurrence of 8 in 1,000 births (1). Advances in pediatric cardiology raised the life expectancy (2) with good quality of life (QoL) (3). Global QoL is often covering physical, communication and emotional concepts (4) or somewhere else defined as a degree of overall life satisfaction that influenced by individuals' perception (5). To assess the factors that influence QoL and its domains many investigations have been performed on children and adolescents with chronic disease such as heart disease (5).

The relationship between higher levels of socioeconomic status (SES) and higher QOL has well been established in

children (4, 6-8). Inequalities can be observed in different SES indicators (9), income disparity may shows access to resources as a financial capital (10-12). whereas occupational prestige is viewed as measuring skill capability (10) and education reflects knowledge about health-related behaviors (10). It has been shown that SES during life is associated with QoL (4, 12). To date, studies of QoL among CHD children have reported contradictory findings, poorer QoL is related to cardiac instability, greater disease severity, poorer motor functioning and autonomy, although no differences were found for some background variables (13). Some previous studies have been found poorer psychological well-being and QoL in CHD patients, when others showed no difference (13)

and some reported better QoL(3, 4). The objective of the present study was measuring QoL among children with CHD and determining the associated factors based on parents' proxy-reports.

Methods

Study design and population

This cross-sectional study was performed to measure QoL in children with CHD and to determine the associated factors. The study performed on CHD children who referred to the heart clinic of Ali Asghar hospital, Zahedan, Sistan and Baluchestan province, Iran in 2016. The study population consisted of parents with CHD children aged from 6 months to 18 years. After consulting with a cardiologist, children with identified chromosomal anomalies and other genetic syndromes and children with major chronic diseases were excluded from the study. Ethical consent and assent were obtained from the eligible candidates for participation in the study. The participants were told about the purpose and benefits of the study and requested to take part in the study. An independent researcher obtained informed consent from qualifying participants and provided instructions on completing the questionnaires. All interviews were conducted at the hospital in a peace and sound location.

Study variables

The questionnaire that provided to the participants consisted of two main segments; the first part included demographic, socioeconomic and clinical measures and the second part was PedsQL 3.0 standard inventory.

The demographic indexes were age, sex, number of household members, living place and transportation status. Socioeconomic indexes included parental education and occupational prestige, Family income, living house status and transportation cost. Clinical parameters were period of referral to the clinic, diseases status and family history of heart failure.

HRQoL assessment tool

The Peds QL 3.0 has two self-report and proxy-parent report. while pediatric patient self-report should be considered as the standard for measuring perceived HRQoL, there may be circumstances when the child is too young, too cognitively impaired, too ill or fatigued to complete a HRQoL Instrument, and parent proxy-report may be used in such cases (14).

This has been justified because children's lack of necessary cognitive and linguistic skills for self-completion of QoL measures. significant internal consistency reliability (> 0.70) and good construct validity, using the known groups approach, has been demonstrated for the majority of the child self-report subscales of the PedsQL™ for young children (15, 16).

The PedsQL 3.0 scales were composed of parallel child self-report and parent proxy-report formats. To assess the quality of life, parents of CHD children completed the PedsQL 3.0 parental version only. The original English version of the PedsQL 3.0 Cardiac Module was translated into Persian by two faculty members in the field of health followed by a joint discussion to combine the two independent versions into a single. Then this issued version backward to original

language by two Persian-English bilingual persons. This process conducted according to the international guideline for questioner translation (forward-backward translation). A pilot study performed on 25 parents who had CHD children, five in each age group. After that, the efforts of the investigators were devoted to achieving linguistic and conceptual equivalence. The cross-cultural adaptation of the questionnaire was performed during this stage to achieve semantic equivalence (equivalence between words), idiomatic equivalence (equivalent expressions or items needing substitution). The reliability of PedsQL 3.0 Cardiac Module Scale and Subscales assessed by means of Cronbach's alpha. The questionnaire consisted of 6 domains including Heart problems and Treatment, Treatment II, Perceived Physical Appearance, Treatment, Anxiety, Cognitive Problems and Communication. A 5-point Likert scale were used as; 0 = it is never a problem; 1 = it is almost never a problem; 2 = it is sometimes a problem; 3 = it is often a problem; and 4 = it is almost always a problem. The items were reverse scored and linearly transformed to a 0–100 scale (0 = 100; 1 = 75; 2 = 50; 3 = 25; and 4 = 0) so that higher scores indicated a better HRQOL. The mean score was computed as the sum of all the items over the number of items answered in taking into account the missing data.

Statistical analysis

All analyses were performed using SPSS version 19 (SPSS, Chicago, IL, USA). Continuous variables were expressed as mean and standard deviation. Categorical variables described as percent. Student t-test and analysis of variance were used in the analysis of the data. We used multivariate linear regression analysis by enter method to identify and quantify predictors of quality of life in the patients. P-value < 0.05 was considered statistically significant.

Results

The study population consisted of 263 patients. Descriptive of total and domains of quality of life with Cronbach's alpha are presented in table 1. There was good internal consistency for all domain. Table 2 shows demographic characteristics of study population. The sex of patients was not equally distributed, more boys 151(57.4%) took part in the study. The majority of the patients 108(41%) had less than 2 years followed by 2-4 years 65(24.7%). Patient and parent population demographics and patient clinical characteristics are shown in table 2. The majority of fathers 117(44.5%) had own business. Only 18 of mothers were employed and the remaining were housewife. About 9% of fathers had collage and universities education while, the majority had secondary and high school levels. All the respondents did answer the question about family income. However, results in Table 1 showed that the majority of families, 144(54.8%) had monthly income lower than 3000000 Iranian Rials that each USD equals to 40000 Iranian Rials approximately. Most of the patients lived rural areas 243(92.4%). The majority of patients, 115(43.7%) were belonged to families with 3-4 member. The transportation cost was high for the majority of families. Most of the patients was referring to the clinic for checking up every four months.

Table 1. Total and Domain of Quality of Life in Children with Congenital Heart Defect

Age group	Domain	Cronbach's Alpha for	Mean (SD)
< 2 years	Heart Problems and Treatment	0.693	49.8 ± 3.6
	Treatment	0.831	60.9 ± 13.8
	Perceived Physical Appearance	0.719	58 ± 12.5
	Treatment Anxiety	0.701	41.6 ± 14.5
2-4 years	Cognitive Problems	0.69	49.9 ± 17.2
	Communication	0.601	44.2 ± 18.5
	Heart Problems and Treatment	0.763	49.2 ± 16.4
	Treatment	0.752	70.3 ± 14.9
5-7 years	Perceived Physical Appearance	0.857	54.2 ± 12.1
	Treatment Anxiety	0.81	48.6 ± 19.4
	Cognitive Problems	0.73	49.1 ± 16.5
	Communication	0.825	39.1 ± 12.6
8-12 years	Heart Problems and Treatment	0.758	56.9 ± 17.2
	Treatment	0.837	66.8 ± 17.4
	Perceived Physical Appearance	0.75	52.3 ± 12.8
	Treatment Anxiety	0.752	57.1 ± 17.9
13-18 years	Cognitive Problems	0.721	30.2 ± 9.1
	Communication	0.754	38.4 ± 18.4
	Heart Problems and Treatment	0.903	50.4 ± 21.1
	Treatment	0.916	61.3 ± 13.8
13-18 years	Perceived Physical Appearance	0.808	49.2 ± 14.4
	Treatment Anxiety	0.964	56.6 ± 16.1
	Cognitive Problems	0.786	43.5 ± 16.1
	Communication	0.832	44.4 ± 18.5
13-18 years	Heart Problems and Treatment	0.951	67.7 ± 14.3
	Treatment	0.823	78.6 ± 9.2
	Perceived Physical Appearance	0.835	63.1 ± 16.1
	Treatment Anxiety	0.774	79.6 ± 15.2
13-18 years	Cognitive Problems	0.779	58.3 ± 19.4
	Communication	0.773	68.2 ± 15.7

The mean score of total quality of life and its subdomain according to study variables are provided in the attached appendix. The scores of QoL and its domain increased significantly with age. There was no significant association between sex of the patient and quality of life. The transport status to heart clinics specified as easy, normal and hard. The results showed that the transport status to heart clinics had significant association with overall QoL and the two domains of heart problems and physical activities. Re-hospitalization was significant only on anxiety as a domain of quality of life (P-value=0.018). The number of household was significantly associated with QoL in the domains of cognition (P-value=0.008), and physical activities (P-value = 0.013). Families with lower members had higher QoL in these two domains. Fathers with Governmental job expressed higher level of QoL and its subdomain except for physical activities. Employed mothers reported higher level of QoL (54.34 ± 12.95) in overall and the domains of heart problems (55.95 ± 15.07), treatment (72.91 ± 10.74) and communication (46.78 ± 14.74) for their children. The analysis showed that the association of mother occupation on QoL in CHD children was not significant. Father education had significant relationship with overall QoL (P-value=0.015) and cognition domain (P-value=0.012). Higher educated mothers declared for the higher score. In the majority of domains and the overall QoL, parents with higher income declared higher quality of life for their CHD children. The domains that influenced by this factor were heart problem, anxiety, communication and overall QoL. Parents who lived in rural area showed that their perception about their children's QoL is higher than those parents who lived in urban areas. Almost for all domains the difference between

rural and urban parents Quality of life perception was not significant.

The results of multivariate linear regression analysis using forward stepwise model are shown in table 3. The strongest predictor for heart problem as a domain of the global QoL was the mother education ($\beta = 3.016$) followed by children age ($\beta = 2.756$). For the domain of treatment, only age had significant level of prediction ($\beta = 2.239$). Physical appearances domain, predicted by number of household members ($\beta = -2.710$) and type of diseases ($\beta = -3.390$, P-value = 0.39). Anxiety as a domain that effete on mental and psychological aspects, the level of its quality effected by age ($\beta = 6.857$) and transport status ($\beta = -3.231$, P-value = 0.026). On communication aspect of QoL in CHD children only the factor of income was significant ($\beta = 4.055$). Cognition had three models because of three significant factors with the strongest impact in given orders of income ($\beta = 4.263$), household ($\beta = -3.035$) number in negative impact and age in negative impact ($\beta = -2.778$). Quality of CHD children life affected by three factors significantly. The factors were income ($\beta = 2.450$), age ($\beta = 1.571$) and number of household members ($\beta = -1.976$).

Discussion

This study was important due to assessing the association of different demographic, socioeconomic, and clinical factors based on parents report on the QoL of their children with CHD. To our knowledge, no other published report included all these variables, highlighting the relevance of this study to the goal of assisting individuals with CHD.

Table 2. Demographic and Familial Characteristics of Study Population

Variables	Number	Percent
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Age groups		
< 2	108	41.1
2-4	65	24.7
5-7	52	19.8
8-12	27	10.3
13-18	11	4.2
Father occupation		
Jobless	28	10.6
Worker	58	22.1
Government employee	60	22.8
Own-business	117	44.5
Mother occupation		
House-wife	245	93.2
Employee	18	6.8
Father education		
Illiterate	69	26.2
Primary school	60	22.8
Secondary and high school	111	42.2
University	23	8.7
Mother education		
Illiterate	106	40.3
Primary school	52	19.8
Secondary and high school	87	33.1
University	18	6.8
Family income per month		
< 3000000 IRR	144	54.8
3000000-5000000 IRR	76	28.9
5000000-10000000IRR	30	11.4
> 10000000 IRR	13	4.9
Gender		
Girls	112	42.6
Boys	151	57.4
Living house status		
Rental house	78	29.7
Own house	185	70.3
Living place		
Urban	20	7.6
Rural	243	92.4
Household number		
3-4	115	43.7
5-7	105	39.9
> 7	43	16.3
Transportation cost		
Low	28	10.6
Medium	112	42.6
High	123	46.8
Period of referral to the clinic		
< 2 months	82	31.2
Every 4 months	95	36.1
Every 6 months	69	26.2
Annually	17	6.5
History of Heart Failure		
Yes	31	11.8
No	232	88.2

The present study showed that the strongest predictor on QoL was mothers' education. For the domain of treatment, only age had a significant impact on QoL. The physical appearance domain influenced by the number of household members and type of diseases factors. Anxiety as a domain of QoL was related with mental and psychological aspects. On communication aspect of QoL only income was a significant predictor. Cognition influenced by income, household number and age. Numerous factors may effect on QoL in CHD children during their growth. Regarding age, children are totally dependent on parents during infancy and childhood (17). Analyzing data of the present study showed that low QoL observed for younger children. Eslami et al., (18) and Durmaz et al., (19) showed that younger age had higher QoL and decreased by age in adults. The difference between these studies was due to the participants' age. Young children and their families might have no clear understanding of the causes and the outcome of their disease condition and so, it confirmed that children of low age are at a higher risk of poor QoL (3, 20). Gender is also reported to be associated with QoL but findings are contraversial. Some studies have found that boys were more at risk of anxiety and behavioral disorders. Boys with CHD may have psychological disturbance because of more community exposure and girls were found to have poor QoL compared to their counterparts (17). In many cultures, boys start interacting earlier than girls. The physical restrictions due to the disease may result in isolation by peers. This separation affects the child psychologically and may lead to anxiety and behavioral disorders. In the present study, low QoL in all the domains observed for the girls. The results of the present study showed that some of the socioeconomic factors had significant association with QoL but, mother education and income had stronger and significant effects. In a recent study, the findings recommended that family income had the greatest influence on QoL (6). Vigl et al. concluded that Socio-demographic factors can be significantly associated with the QoL in CHD patients (21). Eslami et al., reported that being employed, less emotional distress, and higher social support were significantly associated with higher perceived QoL in the most domains (18). Drakouli et al., reported that the socio economic factors play an important role in changing the level of QoL in patients with CHD (22).

Table 3. Predictors of Total Quality of Life and Its Domains in the Patients Using Stepwise Linear Regression Method

Domains	Predictor	B coefficient	t-value	P-value
Heart problem	Age	2.756	3.286	0.001
	Mother education	3.016	3.052	0.003
Treatment	Age	2.239	2.777	0.006
	Household number	-2.611	-2.366	0.019
Physical	Types of diseases	-3.390	-2.077	0.039
	Age	6.857	7.683	0.000
Anxiety	Transportation status	-3.231	-2.241	0.026
	Income	4.055	3.218	0.001
Communication	Household number	-3.035	-1.938	0.054
	Income	4.261	3.389	0.001
Cognition	Age	-2.778	-2.767	0.006
	Income	2.450	3.680	0.000
Total quality of life	Age group	1.571	2.944	0.004
	Household number	-1.976	-2.397	0.017

The patients graduated from high school or university thought that their CHD children had higher QoL than those

graduated from primary and/or secondary schools (23). In particular, before the diagnosis, the parental education was

associated with the absence or delay in seeking medical assistance, and thereby with the worsening of health (24).

Durmaz et al., showed that income had a strong and significant effect on QoL in CHD patients and family with higher monthly income enjoy a better QoL (19). Parents with low educational and income level tend to have difficulties in recognizing their children needs and advisory support, or they ignore its importance and consequently, their children show symptoms of anxiety, depression or even aggressive behavior towards the environment. Also, poor financial status of the family is positively correlated to poor assessment of QoL. Given the fact that the patients need frequent hospital visits and this event make parents worry about the hospitalization cost, resulting in financial problems (25).

Azhar et al., concluded that educated and wealthy parents more tolerate this event and the consequence could be an enhance in the levels of QoL and the domains (26).

Other important factors that should always be taken into account when assessing the QoL in CHD children are family factors such as household number and living area, that affect children's reaction to the disease, as well as their health progress over time. It was well established that family is a dynamic team of inter-dependent members, which are in constant interaction (27).

Another important factor that should always be taken into account when assessing the health related QoL is the family environment because it affects children's reaction to the disease. Therefore, family environment that develops the relations of members of household and the parents' personality is crucial for the outcome of child's disease, children's role in household, child's relationship with the other members of household and these forming the level of acceptance of the disease and helping child's response to stress caused by disease (26, 28).

Children with CHD experience anxiety and depression due to re-hospitalization, the daily medication and the limitations imposed by the disease. In the majority of cases, depression is unrecognized, either because health professionals consider it inevitable or because children are not able to seek help. On the contrary, patients with complex heart diseases and those who are at the end-stage tend to express anxiety and depression, as the fear of imminent death (29, 30).

Present study found that re-hospitalization influence only anxiety domain. Anxiety and depression maybe resulted from re-hospitalization and transportation cost or even the status of transporting to the heart clinic for routine check-up that may influence on QOL in children with CHD (31).

Azhar et al., (26) reported that one third of the children had frequent hospital admissions in relation with CHD and this factor almost impact families' perception about the QoL in their CHD children and believe that impaired physical growth. In accordance with this feature another study reported the frequent and prolonged hospitalizations had a negative impact on the QoL of CHD children due to stress (32).

Manlhiot et al. (33) demonstrated that children with CHDs

who had healthy siblings had low QoL, suggesting that affected children may compare their physical abilities unfavorably with their healthy sibling.

This study suffer from some limitation including cross-sectional nature of the study that preclude for assessing temporal association. Additionally, the income distribution for the sample does not reflect the general population of the province.

Conclusion

The study found some important predictors of quality of life in children with CHD. The results can be used for further educational and supportive programs for these patients.

Acknowledgements

None.

Ethical consideration

The study was approved by the local research ethics committee of the Zahedan University of Medical Sciences, Zahedan, Iran in accordance with the Helsinki Declaration.

Conflicts of interests

Authors declared no conflict of interest.

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