

# ORIGINAL ARTICLE

## Is there any difference in the scores of life quality between mothers of children with congenital heart diseases in need of cardiac surgery and mothers of healthy children?

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### Abstract

**Introduction:** Congenital heart abnormalities are the most common type of congenital conditions in children. Annually, about 1 to 2 percent of children are born with these diseases. As chronic diseases, congenital conditions of children usually cause limitations in the quality of their lives, especially if they are in need of frequent and complex surgical procedures. Regarding the role of parents, especially mothers, in the care of these children, their quality of life is of particular importance. This study, therefore, aimed to evaluate and compare the life quality of mothers with healthy children and mothers with children with a congenital heart disease in need of surgery.

**Methods:** This research is a cross-sectional descriptive-analytical study, in which 100 mothers of healthy children and 60 mothers of children with severe congenital heart disease – who were referred to Birjand Valiasr Hospital in 2017 – were entered into the study. The life quality of the mothers was assessed using the Life Quality Questionnaire of World Health Organization (WHOQOL-BREF). Data were analyzed by SPSS software (version 22). P-values less than 0.05 were considered significant.

**Results:** According to the findings of this study, the age means of the mothers with healthy children and that of mothers of children with congenital heart disease were  $31.91 \pm 8.57$  and  $32.48 \pm 6.46$  years, respectively. The mean score of life quality of mothers with healthy children was  $71.25 \pm 16.43$ ; it was  $41.25 \pm 19.27$  for mothers of children with congenital heart diseases in need of surgery. Life quality and all its sub-scales (social relationships, mental health, environmental health and physical health) were significantly higher in mothers with healthy children than in mothers of children with severe congenital heart diseases in need of surgery before operation ( $P < 0.001$ ).

**Conclusions:** It was found that the life quality of mothers with children with severe congenital heart disease was significantly different from that of mothers with healthy children. Therefore, in order to improve their quality of life, appropriate planning in different areas should be performed.

**Key Words:** Life Quality; Congenital heart disease; Mothers; pre-operation

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## Introduction

Congenital heart diseases are a health threat which causes physical and mental disabilities in children and adults. They are one of the main causes of death in the first year of life (1) and the most common fetal defect at birth, which is seen in 0.5-0.8% of neonates (2). The exact cause of congenital heart disease is often unknown, but environmental and genetic factors influence its pathogenesis (3-9).

Ventricular septal defects, aortic stenosis, atrial septal defect, pulmonary artery stenosis, and aortic coarctation comprise 85% of congenital heart diseases whereas the remaining 15% includes the more uncommon cyanotic types of congenital heart diseases. According to the studies performed in Iran in 2015, the need for intervention in these patients includes, in order of prevalence, the ventricular septal defect surgical closure, the creation of Blalock-Taussig shunt, the correction of tetralogy of Fallot, the correction of aortic coarctation, the operation of arterial switch, the closure of patent ductal aerosols, and the closure of atrial septal defect (10). 40-50% of congenital heart diseases could be detected in the first week of life and 50-60% in the first month (11).

Before 1940, more than 90% of infants with a congenital heart disease would die before puberty. But with recent advances in neonate heart surgeries, more than 90% of them reach the age of 18. There are one million of such children in America, and 200,000 in the UK (12). In Iran, however, there is no accurate record of the prevalence of this disease, but in a study conducted in Ahwaz city, it was estimated to be 12.3 per 1000 live births (1).

Over the past few decades, new techniques and improvements in medical care have reduced the death rate of neonates and children with the most complex congenital heart disease to less than 10% (13). But despite these improvements and the increase in survival rate, the life-threatening state of congenital heart diseases limits the quality of life, especially if it requires frequent and complex surgical treatments (13). Congenital heart diseases cause fundamental changes in the life of children and the whole family, leading to psychological problems, physical activity constraints, and economic problems.

On the other hand, children and families face many challenges during the course of treatment (14). The parents of these children are concerned about their children's future as well as the treatment plan and prognosis of the disease and, thus suffering from psychological problems (15). In

addition to emotional tensions, the family may have to face different problems such as the symptoms of the disease, drugs and their side effects, and non-pharmacological issues such as helping the child to cope with new conditions (16). Therefore, understanding the performance of the parents physically and psychologically and their coping experience is of great importance for health planning (17).

Psychological problems are important in that they can affect the quality of life of the patients before cardiac surgery. At the beginning of the recovery period, patients face symptoms such as anxiety, stress, and depression (18-21). These symptoms can be accompanied by other symptoms such as tiredness, sleep disorders and changes in mood including stress, panic, confusion, restlessness, irritability, and anger due to feelings of worthlessness, and lack of control and self-esteem (22, 23).

As primary caregivers, parents, especially mothers, are faced with numerous problems due to the changes in their parenting function (24) so much so that family caregivers are considered as covert patients (25). They may experience depression or anxiety (26). Personality traits, stressors, stress assessment, coping strategies, and social support are the factors that affect the life quality of caregivers (27).

Family members, as caregivers, influence the patient's ability to cope with the disease (28) and play a central role in managing various aspects of patient-caring (29).

Several studies have been conducted in the domain of life quality in different groups of patients in Iran, however, information about the life quality of parents who have children with developmental disorders is rare and limited to a handful of studies on the quality of life of mothers of children with asthma and diabetes (30), the quality of life of mothers of children with thalassemia major (31, 32), the quality of life of blind children with their peers (without considering the life quality of their mothers) (33), and the quality of life of mothers of children with neuro-developmental disorders such as cerebral palsy and mental retardation (34). There are also few studies on the quality of life of parents with children with congenital heart diseases.

Considering the problems of the families with children in need of special care and taking into account the chronic nature of the disease which greatly affects the life, the care for the whole of the family - which would preserve and integrate the family and promote the health of the child and the family - is of great importance. Thus, this study aims

to compare the quality of life of mothers with congenital heart diseases in need of surgery on pre-operation period mothers of healthy children.

## Methods

The present study was a cross-sectional analytical one. The target population was mothers of healthy children and mothers with severe congenital heart diseases need of surgery who lived in the city of Birjand. Sampling was complete including all mothers of children with severe congenital heart diseases candidate for cardiac surgery who referred to Birjand Vali-e-Asr Hospital in 2017. The sample consisted of 160 mothers including 100 mothers of healthy children and 60 mothers who had a child with congenital heart diseases in need of surgery. The children were selected on the basis of the diagnosis of a pediatric cardiologist and cardiac surgeon and also based on their need for surgery. Mothers of healthy children were selected from among the relatives or the neighbors of the mothers with children with heart disease who had only one child and wanted to fill in the questionnaire.

This research was registered at the Ethics Committee of Birjand University of Medical Sciences with the ethics code REC:1395-255.

After justifying the mothers and obtaining written informed consent from them, the questionnaire of life quality was distributed between the group of mothers with children in need of surgery and the group of mothers with a healthy child. The inclusion criteria were: 1. congenital heart diseases proven in the children under 18 years of age, the 2. need for corrective or reconstructive surgery, 3. mothers' inclination for collaboration, 4. mothers' literacy, 5. and mothers' access to the questionnaire at the right time. The exclusion criteria included: 1. Having two or more children with congenital heart diseases, 2. mental instability, 3. disease or disability affecting the life quality of the mothers of children with congenital heart diseases, and 4. asthma or excessive obesity in the children.

For this purpose, the World Health Organization questionnaire of life quality was used. This questionnaire (WHOQOL-BREF) measures the general life quality of individuals and has 26 questions on a Likert scale. It consists of 4 subscales (physical health, mental health, social relationships, environmental health) and a general score. The internal consistency was also calculated using Cronbach's alpha and the test reliability coefficient was determined to be 0.77 for physical health, 0.77 for mental health, 0.75 for social

relationships, and 0.84 for environmental health. After obtaining the raw scores of each sub-scale, they were converted to a standard score from 0 to 100. A higher score indicates a higher quality of life.

Then, the questionnaires were collected and the data were entered into SPSS software (version 22). The data were analyzed by using central indexes, dispersion, and frequency charts, and appropriate statistical tests; and after determining the normal distribution of the data, T test and Mann-Whitney test were performed at an error level of 5%. P-values less than 0.05 were considered significant.

## Results

In this study, the life quality of 100 mothers of healthy children and that of 60 mothers with severe congenital heart diseases need of surgery were investigated. According to the results of this study, the age range of mothers was 18 to 57 years and the mean age of mothers of healthy children and mothers of children with congenital heart diseases were  $31.91 \pm 8.57$  and  $32.48 \pm 6.46$  years, respectively. The mean score of general health (quality of life) of mothers of healthy children was  $71.25 \pm 16.43$  and  $41.42 \pm 19.27$  for mothers with a child with congenital heart diseases in need of surgery in the pre-operation period.

According to Table 1, the educational level of mothers with children who have congenital heart disease was generally lower than that of the healthy group, and the majority of mothers of children with congenital heart disease were housewives.

The life quality of mothers was not significantly related to their age, education level, and occupation.

Using the Kolmogorov-Smirnov test, the normality of the scores of life quality subscales was tested. Only environmental health score followed the normal distribution. Therefore, the parametric independent t-test was used for this variable. As for the other subscales, the Mann-Whitney nonparametric test was used.

As shown in Table 2, the quality of life of the mothers of healthy children was significantly higher than that of mothers with children with severe congenital heart diseases need of surgery. Moreover, the mean scores of social relationships, mental health, environmental health, physical health, general quality of life, and environmental health in mothers with a healthy child were higher than those of mothers with children with congenital heart diseases in need of surgery.

**Table 1: Frequency distribution of demographic characteristics of mothers of healthy children and mothers of children with severe cardiac diseases before surgery**

Variables		Mothers of healthy children N (%)	Mothers with congenital cardiac disease N (%)
<b>Education</b>	Below high school diploma	16 (16.0)	27 (44.0)
	High school diploma	40 (40.0)	18 (30.0)
	Tertiary	43 (43.0)	15 (26.0)
<b>Occupation</b>	Housewife	53 (53.0)	54 (90.0)
	Employee	32 (32.0)	5 (8.0)
	Self-employed	14 (14.0)	1 (2.0)

**Table 2: Comparison of life quality of mothers with a healthy child and mothers of children with congenital heart diseases in need of surgery before the operation**

Variables		Median (Q1-Q3)	P-value (Mann-Whitney U)*
<b>Social relationships</b>	mothers with a healthy child	66.67 (58.33-75.00)	<0.001
	mothers of children with congenital heart diseases in need of surgery	50.00 (33.33-60.42)	
<b>Mental health</b>	mothers with a healthy child	64.58 (54.17-75.00)	<0.001
	mothers of children with congenital heart diseases in need of surgery	37.50 (29.17-50.00)	
<b>Physical health</b>	mothers with a healthy child	64.29 (57.14-75.00)	<0.001
	mothers of children with congenital heart diseases in need of surgery	28.57 (17.88-33.03)	
<b>general health</b>	mothers with a healthy child	75.00 (62.50-87.50)	<0.001
	mothers of children with congenital heart diseases in need of surgery	50.00 (25.00-50.00)	
Variables		Mean(±SD)	P-value (T-test)
<b>Environmental health</b>	mothers with a healthy child	66.31(±14.18)	<0.001
	mothers of children with congenital heart diseases in need of surgery	49.88 (±12.29)	

\*Statically significant

## Discussion

Diseases affect people's quality of life. In addition to psychological stress to families, children's diseases increase the prevalence of many physical illnesses and psychological disorders such as depression and anxiety in families, especially mothers (4, 35, 36). These diseases and disorders reduce the quality of life of mothers with sick children.

The study of Fourjan et al., (2017) showed that the quality of life of mothers who have a child with a congenital heart disease was lower than that of mothers with healthy children (37).

In a study by Alavi et al (2007), the score of life quality of all mothers with a thalassemia child was  $1.43 \pm 0.88$ . The pedsqlifequality questionnaire was used, in which higher scores indicated more problems, and thus, lower quality of life (31),

which is consistent with the results of our study. As we showed, there is a significant difference between the quality of life of mothers of healthy children and mothers of children with congenital heart diseases in need of surgery, with the average score  $71.25 \pm 16.43$  and  $41.25 \pm 19.27$ , respectively.

Khayyat-Zadeh et al (2009) reported a lower quality of life in mothers of children with cerebral palsy and mental retardation compared to mothers of healthy children. The overall score of life quality in mothers of healthy children was 14, but it was 12.1 in mothers of children with cerebral palsy and 11.9 in mothers with a mentally retarded child (34), which is consistent with the results of our study (34).

Arnaud et al in their study (2008) reported the physical health of mothers of children with cerebral palsy  $55.9 \pm 20.1$ , the score of their mental

health  $71.7 \pm 15.8$ , that of social relationships  $49.1 \pm 23$ , and environmental health  $72 \pm 17.9$  (35).

Arefe et al in their study on heart disease (2008) reported the general health of mothers of children with heart disease  $46.25 \pm 23.59$  ( $41.25 \pm 19.27$  in our study) and that of mothers of children with mild disease  $73.15 \pm 22.03$  ( $71.25 \pm 43.16$  in our study). The subscale of physical health in mothers of children with heart disease was  $39.53 \pm 34.35$  ( $28.89 \pm 13.33$  in our study) and in mothers of children with a mild heart disease was  $61.81 \pm 39.89$  ( $65.18 \pm 13.88$  in our study on healthy children); mental health in mothers of children with heart disease was  $72.90 \pm 16.71$  ( $39.75 \pm 12.96$  in our study on healthy child) and in mothers of children with mild heart disease was  $82.67 \pm 15.12$  ( $54.17 \pm 22.77$  in our study on healthy child); social relationships in mothers of children with heart disease was  $93.21 \pm 23.31$  ( $45.33 \pm 22.35$  in our study), and in mothers of children with mild cardiac disease was  $99.88 \pm 2.8$  ( $57.64 \pm 21$ ) (38).

The study of Khanjari et al on leukemia patients (2013) reported lower life quality for mothers with unwell children than mothers with healthy ones. The average score of life quality of the research units was less than 50% of the total score of life quality – that is,  $62.17 \pm 35.35$ ; it was  $47.8 \pm 18.9$  in physical and mental suffering,  $16 \pm 6.86$  in lifestyle disruption,  $22.65 \pm 45.33$  in a positive adjustment, and  $21.20 \pm 2.45$  in economic worry. The mean score related to positive adaptation indicated more than half the score in proportion to the maximum possible score, whereas other areas of life quality obtained less than half the maximum score possible (39). The results of our study also indicated a significant difference in the quality of life between mothers of healthy children and mothers of children with congenital heart disease in need of surgery; their average score of life quality were  $71.25 \pm 16.43$  and  $41.25 \pm 19.27$ , respectively. The investigation of the dimensions of life quality, in our study, also showed that the median of sub-scales (social relationships, mental health, physical health, and environmental health) in mothers of healthy children was significantly higher than that of mothers of children with congenital heart diseases. Physical health and social relationships had the highest score.

Our findings were also in line with the results of the study by Lawoko and Soares. They found out that mothers of children with congenital heart disease had the lowest quality of life than all other groups, putting them at risk of chronic mental problems (40). The study by Market also showed that the life quality of children and their parents in

the heart disease group was less than that of the normal group. The overall health score of mothers of children with heart disease was  $86.66 \pm 12.28$  and in mothers of healthy children it was  $87.86 \pm 12.19$ ; it was  $88.68 \pm 15.14$  for physical health of the mothers of children with heart disease and  $89.82 \pm 15.43$  in mothers of healthy children; it was  $85.13 \pm 12.26$  for mental health in mothers with a child with heart disease and  $86.56 \pm 12.31$  in mothers with a healthy child; and it was  $90.54 \pm 11.45$  in mothers with a child with heart disease and  $88.54 \pm 15.58$  in mothers of healthy children (41).

Based on variables such as age, education status, and occupation, the mothers were studied in two groups with no significant difference between the two, which was consistent with the results of the studies by Khayyat-Zadeh, Khanjari et al, Turkoglu, and Klinik (29, 34, 39). The reason for this lack of difference can be due to the high stress of the parents concerning the child's illness, and even higher level of education could not change the life quality of the parents.

## Conclusions

According to the results of the study, the life quality of mothers of children with severe congenital heart diseases need of surgery was significantly different than that of mothers of healthy children. Therefore, proper planning in different areas is required to improve their quality of life.

This difference can be due to various factors such as the difficulty of tending to a child with mental illness as well as the concerns about the future of the child. Thus, the mothers of sick children spend more time with the child than the mothers of healthy children. They also have to care and cater for these children and spend a lot of time providing hygienic care, doing therapeutic exercises, coping with behavioral problems, and bringing them to different health centers; whereas mothers of healthy children do not experience such issues, giving them the time to deal with their affairs and to participate in social, occupational and sports activities.

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**Conflict in interests:** None

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