



Evaluation of quality of life and parental attitudes in patients who underwent atrial septal defect closure in childhood

Original Article

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Abstract

Objective: In this study, we aimed to evaluate quality of life and parental attitudes in children who underwent an atrial septal defect closure procedure with a transcatheter or surgical method in childhood and whether they continued their lives with similar activities to their healthy peers by comparing the two groups. **Methods:** Patient forms to define sociodemographic and clinical features, the Questionnaire for Measuring Health-Related Quality of Life in Children and Adolescents (KINDL) to measure the quality of life of children, and the Parent-Child Relationship Test (Parental Attitude Research Instrument) to measure parental attitudes were used. **Results:** The groups were similar in terms of age and sex. The mean quality of life scale scores were high in all groups, and there was no statistically significant difference between the scores. Parents of the patients who underwent closure received higher scores from the demographic attitudes and recognition of quality subdimension compared to the parents of the healthy group. **Conclusions:** The quality of life of children with atrial septal defect closure was found to be similar to their healthy peers. Additionally, the effects of surgical or percutaneous closure of atrial septal defect on quality of life are similar. Children with atrial septal defect closure perceive their health status as well as their healthy peers, and this perception does not cause any difference in the attitudes and behaviours of families.

The secundum type atrial septal defect is the most common type, occurring in 50–70% of all atrial septal defect lesions. Isolated secundum atrial septal defect closure can be accomplished with a surgical or percutaneous transcatheter approach. As an alternative to conventional surgery, transcatheter closure has recently been widely applied as the first choice for secundum atrial septal defects with appropriate anatomical features due to its advantages, such as avoidance of cardiopulmonary bypass and its risks, absence of thoracotomy scarring, and shorter hospital stay.^{1,2} In patients who are not suitable for transcatheter closure, the surgical procedure still maintains its priority.

Today, the importance of quality of life is emphasised in the follow-up of many chronic diseases. The World Health Organization's quality of life group defines quality of life as "the subjective perception of an individual's position in life within the cultural context and value system in which they live, in relation to their expectations, standards and concerns."³ For the paediatric patient group, quality of life is defined as "being sufficient in terms of physical, emotional and social life perceived by the child and the family, and a state of complete well-being beyond the environment, the disease and the clinical practices related to this disease."^{4,5} It has been stated that there is a decrease in the quality of life in children diagnosed with CHD and their families.⁶ In isolated atrial septal defects that are intervened in a timely manner, the expectation is a normal life span and quality.⁷ In regard to the child's disease, the difference between attitudes and behaviours of the parents during the diagnosis and treatment of the disease, when the treatment is terminated, and the duties they undertake during this period are important details that should not be forgotten.⁸

Studies on quality of life in children with CHD have focused mostly on untreated groups.^{9–14} There are few studies evaluating quality of life after cardiac surgery in children.^{15–17} In our study, we investigated the effects of different treatment options on the quality of life of children with the same CHD. In this study, we aimed to evaluate quality of life and parental attitudes in children who underwent an atrial septal defect closure procedure with a transcatheter or surgical method in childhood. We also compared whether they continued their lives with similar activities to their healthy peers.

Materials and methods

The study was conducted at Gazi University Hospital Department between October 2018 and November 2018. A total of 60 children between the ages of eight and 18, including 30 patients

who underwent atrial septal defect closure (15 surgical and 15 transcatheter closure), were included in this study. Patients who had atrial septal defect closure at least one year ago and did not have any other chronic disease and one of their parents were included in the study. The other group included in the study was selected from healthy children whose age and gender were similar to the patient group, who presented to the paediatric clinic for any reason but did not have a chronic disease. And again, one of their parents was also included in the study. In addition, at the time of entering the scale results into the computer, nine out of 60 parents who left the scale questions mostly blank were excluded from the study. The responsible researcher interviewed the patient and control groups, explained the purpose and procedure of the study, and obtained consent from the children and parents. Written permission for the study was obtained from the Gazi University Faculty of Medicine Non-Invasive Clinical Research Ethics Committee (08/10/2018, no: 734).

Patient form

The form designed by the researcher included questions evaluating children's age, sex, date of diagnosis, method and date of closure, sociodemographic status of the family, and patients' clinical condition (comorbidity, drugs used, disease-related symptoms, engagement sports activities, etc.)

General quality of life in children (KINDL)

Patients' quality of life was evaluated using KINDL, a general-purpose health quality-of-life measurement tool developed specifically for children and adolescents. The scale has three versions, arranged based on self-reports used by different age groups. In this study, Kid-KINDL was used for children aged 8–12, and Kiddo-KINDL was used for adolescents aged 13–16. The items of the Kid-KINDL questionnaire answered by children and the Kiddo-KINDL questionnaire answered by adolescents consist of 24 items and six dimensions with Likert-type response options ordered from one (never) to five (always). The subdimensions of the scale consisted of physical well-being, emotional well-being, self-esteem, family, friends, and school (school or kindergarten/nursery where daily activities are held). Each dimension consists of four items. While the scores of the subdimensions are calculated independently, the total quality of life score consisting of the combination of these six dimensions is also obtained. For each dimension, the score is calculated by converting the raw scores given to the items to be between 0 and 100. A high score is indicative of good quality of life. The Turkish validity and reliability study of the scale was conducted by Eser et al. in 2008.¹⁸

Parental Attitude Research Instrument

The scale was developed by Schaefer and Bell in 1958 and adapted into Turkish by Le Compte and Öner in 1978.¹⁹ There are five subdimensions and a total of 60 items in the test, which was rearranged in accordance with the conditions of Turkey. These subdimensions include Extreme Motherhood, Democratic Attitude and Recognition of Equality, Refusing Housewifery, Incompatibility of Spouses, and Pressure and Discipline. A separate score is obtained for each subdimension. A minimum of 16 and a maximum of 64 points can be obtained for the extreme motherhood; minimum of nine, maximum of 36 points for democratic attitude and recognition of equality; minimum of 13, maximum of 52 points for the refusing housewifery; minimum of six, maximum of 24 points for the

incompatibility; and minimum of 16 and maximum of 64 points for pressure and discipline. The high scores obtained in each subtest indicate that the attitude reflected in that dimension is approved. An increase in scores in factors other than democratic attitude and recognition of equality indicates negative parental attitudes.

Statistical analysis

The data collected in this study were statistically analysed using the SPSS 21.0 IBM (Statistical Package of Social Science) package programme and nonparametric analysis methods were used for the analysis of the data. Descriptive analysis methods were used for the sociodemographic information of the participants, Mann-Whitney U analysis was used for the comparison of the paired groups forming the sample group, and Kruskal-Wallis analysis methods were used for the comparison of the triple groups. The Pearson correlation analysis method (*p* values) was used to examine the relationship between the dependent variables obtained. Data are presented as frequencies or mean values ± standard deviations. *p* values < 0.05 were considered statistically significant.

Results

There were eight girls and seven boys in the surgical closure group with a mean age of 12.43 ± 3.02 years, nine girls and six boys in the transcatheter closure group with a mean age of 13.6 ± 3 years, and 16 girls and 14 boys in the control group with a mean age of 12.03 ± 2.91 years. There was no statistically significant difference between the groups in gender (*p* = 0.904) and age (*p* = 0.250) distribution. In the surgery group, only one male patient underwent right posterolateral thoracotomy, while the remaining 14 patients underwent median sternotomy. The mean age at diagnosis was 5.64 ± 4.12 years and the mean age at closure was 7.79 ± 3.77 years in the surgery group, while the mean age at diagnosis was 5.47 ± 3.38 years and the mean age at closure was 6.93 ± 2.12 years in the transcatheter group. There was no statistically significant difference between the surgery and transcatheter groups in terms of the age at diagnosis and closure (*p* = 1.000, *p* = 0.610, respectively). Two patients from each patient group stated that they had complaints about the disease. When asked what their complaints about the disease were, one patient from the surgery group reported tachycardia, and the other suffered from occasional pain in the scar tissue of the operation, while both patients from the transcatheter group complained of occasional chest pain. In the surgical group, 14 patients (93.3%) stated that they had incisional scars, five girls (38.5%) stated that they felt discomfort, and five patients in the transcatheter group stated that they had a small scar due to incision in the groin area, but they did not feel any discomfort. When the patient groups were asked whether they could participate in sports activities, only three (20%) patients from the surgical group said that they could not. Reasons for surgical closure for patients who could not attend included restriction of activity by the family, pain in the scar tissue, and strain with excessive effort. Table 1 shows the sociodemographic and clinical characteristics of the groups.

The KINDL subdimension and total scores of the groups are presented in Table 2. The quality of life scores of the healthy control group were similar to those of the healthy population published by Eser et al.¹⁸ All groups received good quality of life scores, and no statistically significant differences were found between the groups in terms of all subdimensions and total scale scores (for all, *p* > 0.05).

Table 1. Sociodemographic and clinical characteristics of the groups*

	Surgical closure group	Transcatheter closure group	Control group	P
Average age (years)	12.43 ± 3.02	13.6 ± 3	12.03 ± 2.91	0.25
Gender				
Girl (n,%)	8 (53.3)	9 (60)	16 (53.3)	
Boy (n,%)	7 (46.7)	6 (40)	14 (46.7)	
Average maternal age (years)	39.27 ± 6.83	40.33 ± 7.26	36.66 ± 5.36	0.757
Average paternal age (years)	42.86 ± 8.43	44.33 ± 7.29	42.21 ± 5.33	0.753
Average age at diagnosis (years)	5.64 ± 4.12	5.47 ± 3.38	–	1.000
Average age at closure (years)	7.79 ± 3.77	6.93 ± 2.12	–	0.610
Active complaint about the disease (n,%)	2 (13.4)	2 (13.4)	–	
Incision scar (n,%)	14 (93.3)	5 (35.7)	–	
Inability to join sports activities (n,%)	3 (20)	0	–	

*n: number, %: percentage, p value (difference between three groups for average age, gender, average maternal and paternal age, and difference between two closure groups for average age at diagnosis and at closure) < 0.05: statistically significant.

Table 2. KINDL subdimension and total score results of the groups*

KINDL	Surgical closure group	Transcatheter closure group	Control group	P
Bodily well-being	79 ± 17.3	81 ± 14	73.6 ± 10.7	0.088
Emotional well-being	83 ± 11.7	83 ± 15.4	79.5 ± 12.3	0.382
Self-esteem	66 ± 24	66.6 ± 19.4	70 ± 20	0.846
Family	85 ± 12.4	83.6 ± 16.9	86 ± 11.1	0.929
Friends	81 ± 17.4	78.3 ± 18.7	80.1 ± 12.6	0.952
School	70.7 ± 15.1	74.6 ± 13.6	71.1 ± 13.8	0.798
Total QoL	77.4 ± 12.6	77.8 ± 10.76	76.7 ± 10.43	0.682

*p value (difference between three groups) < 0.05: statistically significant.

The mean scores of the Parental Attitude Research Instrument Scale subdimensions of the groups are presented in Table 3. While there was a significant difference between the groups only in terms of democratic attitude and recognition of equality subdimension scores ($p < 0.05$), there was no significant difference in terms of other subdimension scores ($p > 0.05$). According to the democratic attitude and equality recognition subdimension mean scores, the control group had the lowest score.

The KINDL subdimension and total scores of each group were compared in terms of sex, and no statistically significant difference was found between the sexes ($p > 0.05$). When the Parental Attitude Research Instrument subdimension scores of the surgical atrial septal defect closure group were compared in terms of gender, a significant difference was found only in the extreme motherhood subdimension score ($p = 0.014$). In the extreme motherhood subdimension, mothers of girls scored significantly higher than mothers of boys. The relationships between age, age at

closure, and the Parental Attitude Research Instrument and KINDL subdimensions were examined in the groups.

In the surgical closure group, statistically significant negative correlations were found between physical well-being and extreme motherhood, emotional well-being and age at closure, self-esteem and incompatibility of spouses, and age at closure ($p < 0.05$).

Discussion

Although transcatheter atrial septal defect closure is the first choice in secundum atrial septal defects, surgical repair maintains its priority for patients who are not suitable for transcatheter closure. In isolated ASDs that are closed on time, quality of life expectancy is close to normal.^{9,20} Our study shows that children with atrial septal defect closure perceive their quality of life as well as their healthy peers, and this does not cause a significant difference in parental attitudes and behaviour. In addition, our study showed

Table 3. Parental Attitude Research Instrument subdimension score results of the groups

Parental Attitude Research Instrument	Surgical closure group	Transcatheter closure group	Control group	P
Extreme Motherhood	45.44 ± 6.97	46.54 ± 8.29	40.5 ± 10.68	0.26
Democratic attitude and recognition of equality	24.56 ± 2.19	26.21 ± 2.46	23.65 ± 3.2	0.009*
Refusing housewifery	28.78 ± 7.89	30.92 ± 8.81	26.32 ± 6.29	0.336
Incompatibility of spouses	12.6 ± 4.09	15.5 ± 3.74	12.26 ± 4.19	0.051
Pressure-Discipline	38.5 ± 7.82	37.57 ± 11.04	33.04 ± 8.8	0.135

*p value (difference between three groups) < 0.05: statistically significant.

that the difference in closure method did not cause any change in the quality of life of atrial septal defect patients. When looking at the literature, it seems that the quality of life after cardiac surgery in children with CHD is almost never similar to that of their healthy peers.^{15,16,21-23} However, it is also observed that the postoperative quality of life of diagnoses such as isolated and uncomplicated atrial septal defect, ventricular septal defect, and tetralogy of Fallot is better than complicated diagnoses.^{15,20-24} However, information about the effects of surgical or percutaneous methods on the quality of life in patients with the same CHD is quite limited. There are few studies in the literature comparing percutaneous and surgical repair in adult patients. When Sun et al. compared patients who underwent atrial septal defect closure with surgical and percutaneous methods, they determined that the quality of life of patients who had atrial septal defect closure with percutaneous methods was better.²⁵ In our study, we found that the quality of life of both groups was similar. In our centre, most of the surgical atrial septal defect closures are performed by minimally invasive surgery (thoracotomy). In the study of Sun et al., median sternotomy was used as the surgical method.²⁵ It is seen with increasing experience that the minimally invasive approach is more comfortable for the patient in the postoperative period.²⁶⁻²⁸ The results of our study also support this.

The study most similar to our study in the literature is the study of Yuan et al.²⁴ Yuan et al., out of a total of 199 paediatric patients diagnosed with atrial septal defect and ventricular septal defect, compared the quality of life of 83 patients who were treated with percutaneous surgery and 116 who were treated with minimally invasive surgery. They found that the quality of life of both groups improved, but patients treated with the percutaneous method had better quality of life in the early post-treatment period.²⁴ In our study, we found that the quality of life of patients repaired by percutaneous method and patients repaired by minimally invasive surgery was similar to their healthy peers. As the use of minimally invasive surgery and therefore experience increases, the success of minimally invasive surgery may also be increasing.

Parents of infants born with complex CHD experience extreme stress that starts at the time of diagnosis and continues after the infant's hospitalisation, postoperative course, and discharge.^{29,30} This stress can disrupt parent communication and behaviour, and affect the parent's relationship and interaction with the child and other family members.³¹⁻³³ Although the closed groups had higher scores than the healthy control group, there was no statistically significant difference between the groups except for the democratic attitude and recognition of equality subdimension ($p = 0.009$). In our study, it was observed that the lowest score for the democratic attitude and recognition of equality subdimension among the groups was found in the healthy control group, and it was

determined that the CHD process did not cause negative attitudes in the parents. Democratic attitudes include supporting children expressing their feelings and thoughts in every situation. Feeling postoperative pain and distortions in body image can be challenging for most people. Many families may ignore the process rather than confront these feelings. The lack of difference in family attitudes shows that the families in the patient group experience the process as child-centred, and they open up space for their children to express their feelings. The 14 girls' expressions of dissatisfaction with their scars may also be an indication of this.

When all groups were evaluated within themselves, there was no difference between the KINDL total and subdimension scores in terms of gender. In the surgical closure group, five girls (38.5%) of the 14 patients (93.3%) who stated that they had scars were uncomfortable with the scar. In this group, a negative correlation was found between the KINDL bodily well-being subdimension and the Parental Attitude Research Instrument excessive motherhood subdimension, and the subdimensions of the Parental Attitude Research Instrument scale were compared in terms of gender in the surgical atrial septal defect closure group; mothers of girls scored significantly higher than the opposite sex in the extreme motherhood subdimension ($p < 0.05$). The fact that higher body image discomfort in female patients may explain the higher perception of CHD in their parents than in their opposite-sex parents. Unlike our results, Sertçelik et al. investigated the relationship between family-raising attitudes and quality of life in cyanotic and acyanotic congenital heart patients and found a negative relationship between overprotective motherhood and only the psychology subdimension of quality of life.⁹

Considering the relationship between age at closure and quality of life in patients undergoing surgical closure, a significant negative correlation was found between emotional ($r = -.585$, $p < .05$) and self-esteem ($r = -.646$, $p < .05$) subdimensions. As age increases, there is a negative correlation between the self-esteem subdimension in surgical patients. As the age of exposure to surgical stress decreases, the closure process is not remembered, and patients' emotions and self-perceptions are less affected. Here, the family environment and how much the stressful situation is kept on the agenda are very important. The body image of children who listen to the process they have lived through from an early age could be negatively affected. In this study, the democratic attitudes of the families may have reversed this situation.

Cardiac lesions may not always be a major problem in patients, and psychosocial and cosmetic aspects of quality of life may become dominant. The standard approach for most cardiac operations is a vertical median sternotomy, but the vertical median skin scar associated with this procedure can cause psychological distress, especially among younger patients. After puberty, chest

hair may make scars less prominent in male patients, which may explain why female patients are more dissatisfied with their median sternotomy scars than males.³⁴ In our study, five female patients (38.5%) who had undergone median sternotomy stated that they felt significantly uncomfortable with the scars. In a study of 74 adult patients undergoing thoracoscopic atrial septal defect closure, 93% of patients were highly satisfied with procedure-related pain, and 97% felt it left an aesthetically pleasing scar.³⁵ In a study by Kaya et al., cosmetic results of surgery, patient perception, and satisfaction were evaluated in patients who underwent surgical atrial septal defect closure. The study included 26 atrial septal defect patients 14 of whom underwent median sternotomy and 12 of whom underwent right lateral minithoracotomy, with a mean age of 12.4 ± 5.6 years. It was found that total patient satisfaction was higher in the right lateral minithoracotomy group than in the median sternotomy group, and the mean scar length, cardiopulmonary bypass time, and hospital stay were significantly shorter in patients who underwent right lateral minithoracotomy than in median sternotomy patients. In addition, no statistically significant difference was found regarding the skin types of the two groups according to the Fitzpatrick skin type classification scale.³⁶ In another study conducted in Japan, 126 atrial septal defect patients with a mean age at surgery of 7.1 years (1–15 years) underwent a right posterolateral surgical method for closure, and most patients were satisfied with the postoperative cosmetic results.³⁴ In another study conducted in Germany, minimally invasive midaxillarymuscle-sparing thoracotomy was performed on 36 patients (30 girls, 6 boys) with a mean patient age of 6.9 ± 2.6 years. It has been argued that since anterolateral thoracotomy reduces breast development and requires partial transection of large muscle groups for both the posterolateral and anterolateral approaches, the midaxillary approach may help to avoid these side effects and improve the cosmetic outcome, and it is a safe alternative to lateral thoracotomy, which is frequently used in cardiac surgery, for atrial septal defect closure in female patients.³⁷

Thanks to developing surgical techniques today, surgical and percutaneous approaches to atrial septal defect repairs offer similar quality of life. When atrial septal defect needs to be closed surgically, informing patients and their relatives about the incision site and the cosmetic consequences of the incision site is closely related to the effects of surgical results on the quality of life.

Limitations

In our voluntary-based study, because the patients were called by phone and since the patients who underwent closure in our centre continued their follow-up in local centres after the procedure, all patients could not be included in the study, and the patient group selection could not be randomised. In addition, preprocedure quality of life assessment was not performed. Comparison of pre- and postprocedure quality of life outcomes will reflect the potential change that may occur following atrial septal defect closure. However, our study was the first to investigate quality of life and parental attitudes with each other and healthy controls in paediatric patients undergoing surgical or transcatheter atrial septal defect closure. In our study, the effect of surgical and transcatheter atrial septal defect closure on quality of life was evaluated from the perspective of the patients and showed that it did not limit the subjective quality of life of the patients.

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Competing interests. None.

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