

Original Article

School-related adjustment in children and adolescents with CHD

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Abstract Advancements in medical and surgical treatment have increased the life expectancy of patients with CHD. Many patients with CHD, however, struggle with the medical, psychosocial, and behavioural challenges as they transition from childhood to adulthood. Specifically, the environmental and lifestyle challenges in school are very important factors that affect children and adolescents with CHD. This study aimed to evaluate school-related adjustments depending on school level and disclosure of disease in children and adolescents with CHD. This was a descriptive and exploratory study with 205 children and adolescents, aged 7–18 years, who were recruited from two congenital heart clinics from 5 January to 27 February, 2015. Data were analysed using the Student's t-test, analysis of variance, and a univariate general linear model. School-related adjustment scores were significantly different according to school level and disclosure of disease ($p < 0.001$) when age, religion, experience being bullied, and parents' educational levels were assigned as covariates. The school-related adjustment score of patients who did not disclose their disease dropped significantly in high school. This indicated that it is important for healthcare providers to plan developmentally appropriate educational transition programmes for middle-school students with CHD in order for students to prepare themselves before entering high school.

Keywords: Social adjustment; self-concept; school; CHD

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CHD IS THE MOST COMMON BIRTH DEFECT, WITH approximately nine in 1000 newborns being affected.¹ The life expectancy of patients with CHD has increased substantially during the past several decades.² Many patients, however, struggle with the medical, psychosocial, and behavioural challenges that occur from childhood to adulthood.^{3–5} Therefore, problems associated with healthcare of children and adolescents with CHD have become critical.⁶ As children and adolescents spend most of their time in school, health providers should consider school-related adjustment in children and adolescents with CHD. School-related adjustment refers to efforts for coping with stress from various

aspects such as school instruction, school environment, relationships with friends and teachers, and school life.⁷ The factors affecting adolescents' school-related adjustment are multi-factorial and include self-concept, resilience, learning motivation, parental rearing behaviours, and attachment with teachers;⁸ therefore, studies on various topics associated with school-related adjustment in children and adolescents with CHD are needed.

After entering school, children and adolescents with CHD realise that they differ from their peers because they may be excluded from certain physical activities such as gym class.⁹ In addition, most children and adolescents lacked knowledge about their disease, because healthcare providers gave information about their disease only to their parents.¹⁰ Feeling different from their peers and a lack of knowledge about CHD make adolescents

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hesitate to disclose their disease to friends in school. However, it is important for patients with CHD to be open about their disease to effectively manage CHD because they should periodically visit hospitals for follow-up. In addition, there is limited research about school-related adjustments in children and adolescents with CHD, even though this is a very important topic. The purpose of this study was to evaluate school-related adjustment, depending on the school level and disclosure of disease, in children and adolescents with CHD.

Methods

Design

This study was designed as a descriptive and exploratory study to examine school-related adjustment in children and adolescents with CHD.

Setting and samples

Ethics approval for human database research was obtained from the Institutional Review Board of hospitals where this study was conducted. A total of 221 patients were recruited from 5 January to 27 February, 2015, and were asked to complete a self-reported questionnaire. Among all, 16 patients failed to complete the self-reported questionnaire; therefore, a total of 205 patients were included in this study. A total of 205 children and adolescents, 7–18 years of age, who were followed-up at two different paediatric cardiology clinics at university-affiliated tertiary medical centres, were enrolled in this study. Our questionnaire was explained by two research assistants to the participating children and adolescents, as well as their parents. After acquiring consent from patients and their families, we obtained self-reported questionnaires from the patients.

Instruments

Children and adolescents with CHD completed a self-reported questionnaire, which included standardised instruments to measure school-related adjustment and general characteristics.

School-related adjustment

School-related adjustment was measured using a scale developed by Kim.⁷ The school-related adjustment scale was developed targeting 650 elementary-, middle-, and high-school students, and the reliability coefficient of that study was 0.95. It is comprised of 41 items and five subscales. The subscales consist of school environment-related adjustment (nine items), school teacher-related adjustment (nine items), school instruction-related adjustment (eight items), school

friends-related adjustment (eight items), and school life-related adjustment (seven items). Factor analysis was used to verify the validity of school-related adjustment.⁷ The percentage of variance for evaluating the validity of the five subscales was 36.2, 15.1, 11.0, 9.6, and 7.3%, respectively, as listed above, which indicates that this scale had power of explanation.⁷ This self-report instrument uses a five-point Likert scale (1: *strongly disagree*, 5: *strongly agree*), and the scores range from 41 to 205. The reliability coefficient in this study was 0.96. Higher scores indicate the students' better adjustment to school.

General characteristics

Patient age, sex, school level, birth order, religion, experience of being bullied, perceived economic status, NYHA class, type of CHD, and disclosure of disease were assessed. Disclosure of disease was measured using the question "do your friends know that you have a congenital heart disease?", and the corresponding responses were categorised as nobody (no one knows it besides my family), anybody (some of the best friends know it), and everybody (most people know it). Types of CHD were categorised as simple, moderate severity, and great complexity using the Task Force 1 of the 32nd Bethesda Conference of the American College of Cardiology classification.¹¹ Marital status and parental level of education were also assessed as parental characteristics.

Data analysis

The data were analysed using the SPSS 21.0 software. Descriptive statistics were used to define patients' general characteristics and their school-related adjustment. Student's *t*-test, analysis of variance, and Scheffe's tests were conducted to identify the differences in school-related adjustment according to general characteristics. A univariate general lineal model was run to analyse the school-related adjustment score, according to school level and disclosure of their disease.

Results

General characteristics of patients and their parents

The demographics and disease-related characteristics of the patients are shown in Table 1. The median age was 13 years (with a range of 7–18 years) and 114 patients (55.6%) were male. Among all, 87 patients (42.4%) were elementary-school students, 53 patients (25.9%) were middle-school students, and 65 patients were high-school students. Most of the participating adolescents lived with both parents, and 14 (6.8%) patients lived with a single parent. Among the

Table 1. General characteristics of patients and parents.

Variables	Categories	n (%)	Mean \pm SD	Range
Patients' characteristic				
Gender	Male	114 (55.6)	13.44 \pm 3.23	8–18
	Female	91 (44.4)		
Age				
School	Elementary	87 (42.4)		
	Middle	53 (25.9)		
	High	65 (31.7)		
Birth order	First	87 (42.4)		
	>Second	91 (44.4)		
Religion	Only child	26 (12.7)		
	Yes	94 (45.9)		
Experience being bullied	No	111 (54.1)		
	Yes	19 (9.3)		
Perceived economic status	No	186 (90.7)		
	Good	13 (6.3)		
	Average	165 (80.5)		
NYHA class	Bad	24 (11.7)		
	I	138 (67.3)		
	II	57 (27.8)		
Type of CHD	III	8 (3.9)		
	Simple	28 (13.7)		
	Moderate severity	77 (37.6)		
People that know about their disease	Great complexity	100 (48.8)		
	Nobody	31 (15.1)		
	Anybody	91 (44.4)		
Parental characteristics	Everybody	83 (40.5)		
	Married	191 (93.2)		
	Divorce or bereaved	14 (6.8)		
Father's education level	<High school	9 (4.4)		
	High school	61 (29.8)		
	College or beyond	135 (65.9)		
Mother's education level	<High school	10 (4.9)		
	High school	96 (46.8)		
	College or beyond	99 (48.3)		

n = 205

patients' parents, 135 (65.9%) fathers and 99 (48.3%) mothers had a college level or beyond educational status. A total of 178 patients (86.8%) self-described as having above average economic status, and 91 patients (45.9%) practised religion. In addition, 19 patients (9.3%) had the experience of being bullied and 31 (15.1%) patients reported that nobody knew about their disease, whereas 174 (84.9%) patients reported that anybody or everybody knew about their condition. Disease complexity was classified as the three categories stated earlier in this article, and 100 patients (48.8%) had greatly complex CHD. In addition, 138 patients (67.3%) were classified as the NYHA functional class I, and eight patients (3.9%) were classified as the NYHA functional class III.

Relationships between school-related adjustment and general characteristics

The average school-related adjustment score was 151.34 and ranged from 85 to 205. Elementary-school

students scored among the highest levels of school-related adjustment, and high-school students scored the lowest levels of school-related adjustment ($p < 0.01$). Adolescents who indicated that they practised a religion scored higher levels of school-related adjustment compared with those who did not have a religion ($p = 0.03$). The school-related adjustment scores of adolescents who had the experience of being bullied were significantly lower than those of adolescents who did not have the experience of being bullied ($p < 0.01$). The school-related adjustment score was also significantly related to parents' education level ($p < 0.01$) (Table 2).

School-related adjustment according to school level and disclosure of disease

Figure 1 shows the results of the general lineal model analysis. We assigned age, religion, experience of being bullied, and parents' education levels as covariates to investigate the relationship between

Table 2. School-related adjustment according to general characteristics.

Characteristics	Mean \pm SD	t or F test	p	Scheffe's test
Gender		-1.04	0.30	
Male	149.73 \pm 23.92			
Female	153.36 \pm 25.92			
School		7.47	<0.01	a > c
Elementary ^a	158.20 \pm 24.97			
Middle ^b	150.32 \pm 25.09			
High ^c	143.00 \pm 21.91			
Birth order		0.25	0.78	
First	150.24 \pm 25.38			
>Second	152.77 \pm 25.21			
Only child	150.42 \pm 22.57			
Religion		2.25	0.03	
Yes	155.53 \pm 23.83			
No	147.79 \pm 25.21			
Experience being bullied		2.86	<0.01	
Yes	136.11 \pm 27.87			
No	152.90 \pm 24.04			
Perceived economic status		1.06	0.35	
Good	154.46 \pm 19.23			
Average	152.19 \pm 25.54			
Bad	144.67 \pm 22.65			
NYHA class		0.83	0.44	
I	150.58 \pm 25.73			
II	154.00 \pm 23.77			
III	143.00 \pm 17.53			
Type of CHD		2.01	0.09	
Simple	160.79 \pm 23.86			
Moderate severity	150.36 \pm 24.93			
Great complexity	149.45 \pm 24.67			
People that know about disease		0.68	0.51	
Nobody	147.71 \pm 27.41			
Anybody	150.62 \pm 24.93			
Everybody	153.49 \pm 23.80			
Parental marital status		0.96	0.34	
Married	151.79 \pm 25.21			
Divorce or bereaved	145.21 \pm 18.44			
Father's education level		6.62	<0.01	
<High school	147.11 \pm 19.28			
High school	142.30 \pm 23.75			
College or beyond	155.71 \pm 24.62			
Mother's education level		5.06	<0.01	
<High school	152.00 \pm 31.44			
High school	145.68 \pm 23.64			
College or beyond	156.77 \pm 24.28			

n = 205

school-related adjustment, school level, and disclosure of disease; this is because school-related adjustment was found to be significantly related to age, religion, experience of being bullied, and parents' education levels. School-related adjustment scores were significantly different according to school level and disclosure of disease ($p < 0.001$) with regard to age, religion, experience of being bullied, and parents' education levels as covariates. In particular, the school-related adjustment scores of patients who did not disclose their disease dropped greatly in high school (Fig 1).

Discussion

The mean score of school-related adjustment in children and adolescents with CHD in this study was 151.34. The mean score of patients in this study was higher compared with general students in another study using the same measurement for school-related adjustment.^{7,12} The mean scores of school-related adjustment were 103.3 in a previous study on Korean elementary-school students¹² and 119.43 in a study on Korean elementary-, middle-, and high-school students.⁷ Consistent with this study, a previous

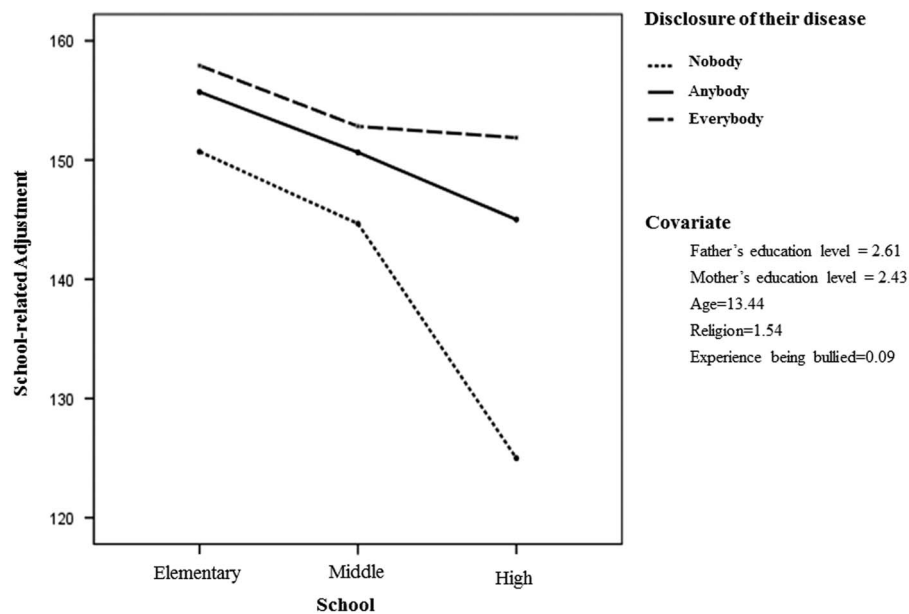


Figure 1.
School-related adjustment according to school level and disclosure of disease.

study using a systematic review revealed a positive outcome from self-reported psychological functioning in children and adolescents with CHD.¹³ In addition, school-related adjustment was not associated with type of CHD. As the majority of patients had received surgery to completely correct their CHD and reported NYHA class I or II, school-related adjustment was not related to the type of CHD. An earlier study found that children with CHD who received a palliative operation and did not undergo a complete correction were more withdrawn and had more social problems compared with general children.¹⁴ Therefore, if children and adolescents with CHD receive total correction surgery and are continuously managed, the type of CHD would not be a predictor of school-related adjustment because of the advanced treatment and management of CHD.

This study found that school-related adjustment scores decline over time such that high-school children with CHD have the lowest adjustment scores. The analysis indicated that these patients tended to have increasing difficulty in adjusting as they advanced through school. The majority of Korean parents think that the most important role of children and adolescents is to enter university, and they further hope that their children enter a prestigious university.¹⁵ Therefore, the aims of education for middle and high school in Korea are not focussed on developing self-identity but are instead focussed on completing requirements for entering university.¹⁶ There is a great deal of pressure for Korean children and adolescents to study for college entrance exams, which increases until students

enter college. Unfortunately, children and adolescents with CHD have difficulty catching up with their studies after returning from long hospitalisations.⁹ Accordingly, children and adolescents with CHD have difficulty adjusting as they advance through school until they enter college.

Our findings also indicate that the school-related adjustment score of patients who did not disclose their disease decreased significantly in high school. Children and adolescents with CHD begin to feel that they are different after entering school, which leads them to feel isolated.^{9,17} They tend to prefer not to tell others about their disease¹⁷ because they fear being pitied.⁹ Therefore, it is difficult to build a relationship with peers; this is a problem because establishing close and meaningful relationships with peers is an important developmental task for adolescents.¹⁸ A lack of such intimate peer relationships may result in feelings of loneliness, defined as the negative emotional response to a discrepancy between one's desired and actual social network.¹⁹ Patients who tried to hide their disease had difficulties establishing close and meaningful relationships with peers, which increased school maladjustment. Therefore, it is important for adolescents with CHD to be able to accept themselves, especially as they enter high school to prevent the significant decline in school-related adjustment.

Children and adolescents with CHD should be well informed about their disease and treatments in order to accept themselves. In addition, accurate knowledge of CHD is associated with improved resilience and health-related quality of life.^{20,21}

Patients with knowledge about CHD and treatment have better compliance and feel a stronger sense of responsibility for their own health.²² However, some adolescents reported that they did not have any opportunity to obtain the necessary information about their disease, because they did not talk about their illness with their family or their healthcare provider.⁹ Clear and accurate information about their condition, given in a developmentally appropriate manner, is a resource that will help adolescents with CHD understand their condition as well as their limitations and abilities in their lives.²³ Knowledge and understanding of their cardiac condition needs to be addressed by health professionals using specific, age-appropriate education programmes to meet the specific psychological needs, as has been done for parents that have a newborn or infant with CHD.²⁴ Therefore, transition programmes that provide peer support, confidential counselling, disease knowledge, and management are important for middle-school students with CHD, in order to help them achieve self-acceptance, especially before they begin high school.

Limitations

The generalisability of this study would be limited because the instrument for measuring school-related adjustment was developed for Korean adolescents.

Conclusions

This study showed that school-related adjustment scores were significantly related to school level and disclosure of disease. School-related adjustment scores decline over time, such that high-school children with CHD have the lowest adjustment scores. The school-related adjustment score of patients who did not disclose their disease decreased significantly in high school. Therefore, it is important for healthcare providers to plan appropriate educational transition programmes for middle-school students that address health conditions and self-acceptance, especially before students enter high school.

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Conflicts of Interest

None.

Ethical Standards

The authors assert that all the procedures contributing to this study comply with the ethical standards of the relevant national guidelines on human experimentation and with the Helsinki declaration, and have been approved by the institutional ethics committees at SHYU, Korea.

References

- van der Linde D, Konings EE, Slager MA, et al. Birth prevalence of congenital heart disease worldwide: a systematic review and meta-analysis. *J Am Coll Cardiol* 2011; 58: 2241–2247.
- Moons P, Bovijn L, Budts W, et al. Temporal trends in survival to adulthood among patients born with congenital heart disease from 1970 to 1992 in Belgium. *Circulation* 2010; 122: 2264–2272.
- Karsdorp PA, Everaerd W, Kindt M, Mulder BJ. Psychological and cognitive functioning in children and adolescents with congenital heart disease: a meta-analysis. *J Pediatr Psychol* 2007; 32: 527–541.
- Fredriksen PM, Diseth TH, Thaulow E. Children and adolescents with congenital heart disease: assessment of behavioural and emotional problems. *Eur Child Adolesc Psychiatry* 2009; 18: 292–300.
- Claessens P, Moons P, de Casterle BD, et al. What does it mean to live with a congenital heart disease? A qualitative study on the lived experiences of adult patients. *Eur J Cardiovasc Nurs* 2005; 4: 3–10.
- Chen CW, Su WJ, Chiang YT, Shu YM, Moons P. Healthcare needs of adolescents with congenital heart disease transitioning into adulthood: a Delphi survey of patients, parents, and healthcare providers. *Eur J Cardiovasc Nurs* 2016; 16: 125–135.
- Kim YR. An analysis on the validation of school learning motivation scale and school-related coping scale, and relations between school learning motivation scale and school-related coping scale. *J Educ Res* 2000; 17: 3–37.
- Bae J. Causal relationships between school adjustment of middle school students and related variable. *J Korean Acad Nurs* 2008; 38: 454–464.
- Lee S, Kim SS. The life experiences of Korean children and adolescents with complex congenital heart disease: a qualitative study. *Nurs Health Sci* 2012; 14: 398–404.
- Ahn JA, Lee S, Choi JY. Comparison of coping strategy and disease knowledge in dyads of parents and their adolescent with congenital heart disease. *J Cardiovasc Nurs* 2014; 29: 508–516.
- Warnes CA, Libberthson R, Danielson GK Jr, et al. Task Force 1: the changing profile of congenital heart disease in adult life. *J Am Coll Cardiol* 2001; 37: 1170–1175.
- Lee HS. The effect of the collective reward and punishment marks system on children's adaptation to school: focusing on the primary-school children in the upper grades. *J Korea Contents Assoc* 2013; 13: 518–528.
- Latal B, Helfricht S, Fischer JE, Bauersfeld U, Landolt MA. Psychological adjustment and quality of life in children and adolescents following open-heart surgery for congenital heart disease: a systematic review. *Pediatrics* 2009; 9: 6.
- Casey FA, Sykes DH, Craig BG, Power R, Mulholland HC. Behavioral adjustment of children with surgically palliated

- complex congenital heart disease. *J Pediatr Psychol* 1996; 21: 335–352.
15. Ryu JH. A study on the parent-child relation, familism, and Hyo. *Korean J Parent Educ* 2007; 4: 81–94.
 16. Yoo J, Kim BM, Shin HS, et al. Relationship with stress from university entrance competitions, self-esteem, coping strategy of high school students in Korea. *Crisis Emerg Manage Theory Praxis* 2010; 6: 223–241.
 17. Berghammer M, Dellborg M, Ekman I. Young adults experiences of living with congenital heart disease. *Int J Cardiol* 2006; 110: 340–347.
 18. Steinberg L, Morris AS. Adolescent development. *Annu Rev Psychol* 2001; 52: 83–110.
 19. Freitas IR, Castro M, Sarmiento SL, et al. A cohort study on psychosocial adjustment and psychopathology in adolescents and young adults with congenital heart disease. *BMJ Open* 2013; 3: 1–8.
 20. Lee S, Kim S, Choi JY. Coping and resilience of adolescents with congenital heart disease. *J Cardiovasc Nurs* 2014; 29: 340–346.
 21. Wang Q, Hay M, Clarke D, Menahem S. Associations between knowledge of disease, depression and anxiety, social support, sense of coherence and optimism with health related quality of life in an ambulatory sample of adolescents with heart disease. *Cardiol Young* 2014; 24: 126–133.
 22. Canobbio MM. Health care issues facing adolescents with congenital heart disease. *J Pediatr Nurs* 2001; 16: 363–370.
 23. Birks Y, Sloper P, Lewin R, Parsons J. Exploring health-related experiences of children and young people with congenital heart disease. *Health Expect* 2007; 10: 16–29.
 24. Caldera K, Ha D, Menahem S. The development of a CD-ROM: an aid to fetal cardiac diagnosis and counseling. *Fetal Diagn Ther* 2013; 33: 61–64.