

Impact of severity of congenital heart diseases on university graduation rate among male patients

Doğuştan kalp hastalıkları ciddiyetinin erkek hastaların yükseköğrenim düzeyleri üzerine etkisi

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ABSTRACT

Objectives: This study examines university graduation rates among individuals with congenital heart disease (CHD) in comparison to their healthy peers. The effect of disease severity, type of surgery, and timing of surgery on graduation rate was also evaluated.

Study design: One hundred forty-five male patients with CHD at military age were enrolled in the study between the dates of January 2005 and May 2007. Severity of disease was operationalised in term of initial diagnosis (According to classification of 32th ACC Bethesda Conference Task Force 1). University graduation rates of among two groups of CHD patients (mild disease (group 1) or moderate to severe disease (group 2)) are compared to each other and to healthy peers.

Results: Patients with CHD have reduced rates of participation in higher education compared with healthy individuals (13.1% vs 20.7%, $p=0.01$). Furthermore, this negative effect on education participation rate is independent of the severity of disease (group 1, 16.4%, $p=0.01$; group 2, 9.7%, $p<0.001$). Although the university graduation rate was relatively higher in patients with mild disease severity, no significant difference was found between the two patient groups ($p=0.23$). Having an operation does not effect graduation rate ($p=0.58$), however greater age at the time of operation increases the likelihood of graduation ($p=0.02$).

Conclusion: Being born with CHD significantly reduces the chance of completing higher education. This negative impact on university graduation rate is independent of the severity of the disease. No negative effects of disease related surgery or subsequent corrective surgery on education were observed. Patients who were operated on later in life were more likely to complete university education. Mean operation age of this group corresponds to the typical age during the last year of elementary school in Turkey.

ÖZET

Amaç: Erişkin yaşa ulaşmayı başaran doğumsal kalp hastalarının (DKH) sağlıklı bireyler kadar yükseköğrenim görme başarısına ulaşma durumları araştırıldı. Aynı zamanda, hastalık ciddiyeti, ameliyat olma durumları ve ameliyat yaşının bu başarıya etkisi değerlendirildi.

Çalışma planı: Ocak 2005-Mayıs 2007 tarihleri arasında kardiyoloji kliniğinde DKH nedeni ile sağlık kuruluna çıkarılan 145 hasta alındı. Hastalıkların ciddiyeti "32. ACC Bethesda Conference Task Force 1"e göre sınıflandırıldı, hastalar hafif (Grup 1) ve orta+ciddi (Grup 2) olmak üzere iki gruba ayrıldı. Her iki gruptaki hastaların yüksek öğrenim oranları kendi aralarında ve aynı zamanda askerlik şubelerine başvuran sağlıklı bireylerle karşılaştırıldı.

Bulgular: DKH'nin üniversite mezunu olma oranları sağlıklı bireylerden anlamlı olarak düşüktü (%13.1 ve %20.7, $p=0.01$). Ciddiyetlerine göre iki gruba ayrılan hastalar sağlıklı bireylerle ayrı ayrı karşılaştırıldığında da sonuç olumsuzdu (Grup 1, %16.4, $p=0.01$; Grup 2, %9.7, $p<0.001$). Grup 1'de yüksek öğrenim oranları görece yüksek olmakla birlikte iki grup arasındaki fark anlamlı değildi ($p=0.23$). Ameliyat olanlarla olmayanlar arasında fark saptanmadı ($p=0.58$). Yükseköğrenim mezunu olan grubun ortalama ameliyat yaşı olmayan gruba göre anlamlı yüksekti ($p=0.02$).

Sonuç: Ülkemizde doğuştan kalp hastalığı ile doğmak, ileride yükseköğrenim görme şansını anlamlı olarak azaltmaktadır. Eğitim düzeyi üzerine olan bu olumsuz etki hastalığın ciddiyetinden bağımsızdır. Hastalık nedeni ile ameliyat olmanın eğitim düzeyine olumsuz bir etkisi gözlenmemiştir. Daha geç yaşlarda ameliyat olanlarda yükseköğrenim mezunu olma oranı daha yüksek bulunmuştur. Bu grubun ameliyat yaşı ortalaması ilkokulu bitirdikten sonraki yaşlara uymaktadır.

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In recent years, the number of patients with congenital heart disease surviving to adulthood has increased due to advances in surgical and medical treatment. Unfortunately, a longer life does not mean a better quality of life. Besides medical problems, these individuals also experience psychosocial, academic, and occupational challenges.^[1-4]

The level of education impacts employment opportunities similarly to the severity of the disease.^[5,6] Intellectual development can be affected by the negative hemodynamic consequences of the cardiac defect. Circulatory arrest, hypothermia, exposure to anesthesia, low cardiac output, acidosis and hypoxia during cardiac surgery are thought to have negative effects on cognitive functions.^[7-9] Moreover, depression and absenteeism caused by chronic diseases are important factors which effect success.^[10,11]

On the other hand, studies on asymptomatic adolescents with mild congenital heart defects are promising. It has been reported that this group of patients does not experience impairment due to CHD during high school and in job-seeking after graduation.^[12] These patients may even display more commitment to their education than the general population, perhaps due to the intensive support of their families and health care professionals.^[11,13]

Higher education is the final stage of the education system. It is important for obtaining both productive employment and social status. In Turkey, there is a central selection and placement examination for higher education. Students all over Turkey enter same examination every year and are placed according to their scores. Both admission and graduation from university requires high intellectual skills and effort.

In Turkey, there is neither a special education programme nor a special examination for students who have chronic diseases. Furthermore, educational data describing adults with CHD are limited. Therefore, this study was conducted to investigate university graduation rates of adults with CHD in comparison to healthy peers. We also evaluated the

Abbreviations:

ACC	American College of Cardiology
CHD	Congenital heart disease

effects of disease severity, type of surgery, and timing of the surgery on graduation rates.

PATIENTS AND METHODS

One hundred forty-five CHD patients who presented to the Impairment Assessment Committee of Military Hospital, Cardiology Clinic between January 2005 and May 2007 were included in this study. Patients with mental retardation, auditory or visual impairment, or who were illiterate were not admitted. Information, such as date of birth, place of birth, initial diagnosis, CHD operation history, if applicable (including the age on the day of surgery and the number of procedures that patient had), and the level of education (specifically, whether the patient is a university graduate or not) were recorded. Suspicious or missing data obtained from hospitals where patients were diagnosed or operated. The study was approved by a local ethics committee. The severity of the diseases was classified according to the 32nd Bethesda Conference Task Force 1 of American College of Cardiology (ACC)^[14] Because of the promising preliminary data regardingt patients with mild congenital defects, patients were divided into two groups (mild and moderate-to-severe disease). Patient groups were compared to each other or to healthy peers. Four hundred healthy consecutive military candidates presenting to the same military office were investigated to determine the rate of university graduates. Men are recruited by military offices in their town and individuals with potential health concerns are referred to military hospitals in that region. Therefore, patients and healthy individuals had similar living conditions and social background. Distribution of the patients according to their diagnoses and their classification according to Task Force 1 is presented in the Table 1.

Statistical analysis

Statistical analysis was performed using the “SPSS package 12.0 for Windows”. Data were expressed as mean±standard deviation and/or as proportions. Categorical and numerical variables were compared using the chi-square test and Mann-Whitney U-test, respectively. A *p* value of less than 0.05 was considered statistically significant.

RESULTS

One hundred forty-five male patients with CHD with a mean age of 23.8 years (SD=3.8; range, 20-42 years) were included in the study. Mean age of the reference group was 23.5 (SD=3.6; range, 20-38).

Table 1. Distribution of patients according to diagnosis and classification recommended by ACC Bethesda Conference Task Force 1.^[18]

Severe	n
Conduits, valved or nonvalved	10
Double outlet ventricle	1
Fontan procedure	7
Pulmoner atresia	1
Transposition of great arteries	2
Moderate	n
Anomalous pulmonary venous drainage	2
Atrioventricular canal defects	3
Coarctation of the aorta	5
Infundibular RV outflow obstruction	2
Ostium primum ASD	2
Patent ductus arteriosus (not closed)	1
Pulmonary valve regurgitation (severe)	2
Pulmonary valve stenosis (severe)	6
Sinus venosus ASD	2
Subvalvar or supra-valvar aortic stenosis (except HCM)	7
VSD with:	
*Aortic regurgitation	8
*RV outflow tract obstruction	6
*Subaortic stenosis	3
*Straddling mitral valve	2
Mild	n
<i>Native Disease</i>	
Isolated PFO or small ASD	4
Isolated small VSD (no associated lesions)	14
Isolated Aortic valve disease	12
Mild pulmonic stenosis	1
<i>Repaired conditions</i>	
Previously ligated or occluded ductus arteriosus	5
Repaired secundum or sinus venosus ASD	25
Repaired VSD	12

ACC: American College of Cardiology; ASD: Atrial septal defect; HCM: Hypertrophic cardiomyopathy; RV: Right ventricle; PFO: Patent foramen ovale; VSD: Ventricular septal defect.

Severity of diseases was mild in 53.3% (n=73) and moderate-to-severe in 49.7% of the patients (n=72). 19 patients (13.1%) were university graduates. This rate was significantly lower than the reference group, which was reported as 20.7% (p=0.01).

Patient groups were also compared with healthy individuals according to the severity of the disease. University graduation rate for both the moderate-to-severe group (9.7%; p<0.001) and the mild severity group (16.4%; p=0.01) were significantly lower than healthy individuals (20.7%). Although the university graduation rate of patients with mild disease was relatively greater, no significant difference was found between the two patient groups (p=0.23).

One hundred seven patients (73.8%) underwent surgery and 4 of these individuals had second operation. University graduate rates were 12.1% for patients who underwent surgery and 15.8% for patients who did not have an operation. The difference was not statistically significant (p=0.58). None of the patients who had second operation (n=4) were university graduates. No statistically significant relationship was found between the number of surgical procedures and university graduation rate (p=1.00).

No clear conclusion regarding the number of surgeries and university graduation rate could be made as there were only four patients who underwent a second surgery. The mean age at the time of the first surgery among university graduates (13.1 years; SS=6.6) was significantly higher (p=0.028) than the non-graduates (9.3 years; SS=6.0).

The difference between the age at the time of entering the military between the two groups (university graduates and non-graduates) was statistically significant (p<0.001) since military obligation is postponed during university education in Turkey. The mean age of patients with no university degree was 23.3 years and the mean age of university graduates was 27.6 years.

DISCUSSION

Chronic disorders such as CHDs, may negatively influence the academic success of children and

adolescents. Congenital heart diseases may cause developmental delay leading to poor physical, psychosocial, and intellectual outcomes,^[15] cognitive deficiency,^[16] and low self-esteem.^[17] Although advances in medical and surgical treatment have helped to cure children with CHD and have resulted in increased life expectancy, a community of children who have experienced academic difficulties due to CHDs has developed.

According to our findings, male patients with CHD have reduced higher education participation in comparison to healthy individuals. In general, it has been previously reported that CHD has a negative impact on the level of education, but there are other studies which have found no negative impact on education for patients with mild cardiac defects.^[6,11-13] However, these studies did not directly investigate the effects on a university education. As far as we know, this is the first study evaluating the effects of severity of CHDs on completion of higher education.

In our study, patients either have severe-to-moderate or mild defects had lower university graduation rates than healthy individuals. University graduation rate was relatively higher in mild group, but it was not significantly different relative to the moderate-to-severe group. Despite previous reports that education is not impacted in patients with mild congenital defects, our contradictory results may be explained by the higher intellectual demands and more intensive study requirements of a university education. It should also be noted that earlier studies have been conducted in modern societies in which these children are able to receive special education.

Although the impact of the severity of the disease on cognitive function is not clear, it has been observed in many studies that the severity of the CHD negatively influences the success of children at school.^[18] Behavioral problems, emotional inconsistency, and hyperactivity and attention deficit disorder frequently occur in these children.^[19] Additionally, deficiencies in executive functions, such as the ability to plan and perform complex tasks, may be present. As the children reach school age, learning disabilities, behavioral problems, and attention deficit/hyperactivity disorder may result in

school failure, poor social skills, low self-esteem and delinquency.^[20-23] Long-term results of these findings and the effects on adult life are not known and need to be investigated. There is limited information because of several variables, such as the type of surgery or surgical technique, heterogeneity due to different forms of CHD, variations in study design, and assessment scales.

According to our findings, undergoing surgery did not negatively influence the likelihood of completing a university degree. However, the mean age at the time of the first operation was greater in university graduates. Undergoing a surgical procedure does not effect the level of education completed ($p=0.58$) but greater age at the time of operation increases the likelihood of educational success (mean age 13.1 vs 9.3, $p=0.02$). A critical issue regarding the best timing for surgical intervention in CHD has emerged in this study. Needless to say, the hemodynamic impact of the cardiac defect should be the main determinant of surgical necessity and timing. However, the effect of the time of lesion repair on cognitive function is still a matter of debate. Even though there are studies suggesting that late operations lead to negative outcome due to prolonged exposure to hypoxia, there are also studies which replicate the positive relationship demonstrated by our study.^[18,24-26] The mean age at the time of surgery among the university graduates was 13 years in our study. This age corresponds to the typical age during the last year of elementary school in Turkey.

These results may be related to the early experience of this traumatic event, which may deeply influence the psychology of children, as well as the neurologic and cognitive responses associated with surgery. It should also be kept in mind that patients with severe lesions and more complex anomalies tend to undergo surgery earlier. Datas suggest that cyanotic lesions need to be corrected at a critical age before the induction of the negative effects of hypoxia.^[24,25] Studies investigating cognitive outcomes related to the timing of surgery in the same group of patients are needed in order to address this question. There is an interesting study evaluating adult patients with an isolated ventricular septal defect who underwent surgery after the age of

10 years.^[13] Education levels among patients who underwent surgery were higher than education levels among patients with a small defect who did not undergo surgery. Ventricular septal defect repair after the age of 10 years did not negatively impact the level of education or cardiac status in adulthood. The education levels of both patient groups were in fact higher in comparison to the healthy population. Even though our data support the findings of this study regarding the age of operation and neutral effects of surgery, we found that the level of education was lower in these patients than among the healthy population. This finding may be indicative of the importance of individual motivation and special education.

Congenital heart disease is a chronic disorder that can lead to academic and psychosocial problems in children by negatively affecting the children's adaptation to the school environment. The increased absenteeism rate in the CHD population also has a negative impact on the adaptation to school. It is not surprising to observe a significant relationship between absenteeism and the severity of the disease.^[11] An increased number of clinical visits among children with CHDs may contribute to an increased absenteeism rate, thereby affecting success in school.^[27] It is a natural choice for children to stay at home instead of going to school due to fatigue and physical problems. Although the cognitive abilities of most CHD patients are within normal limits, a significant number of patients experience learning difficulties and require academic help. Correction of defects and medical treatments must not be the single aim of treatment. Effective treatment of CHD should address the psychological and social impairments resulting from this disease.

Our study reflects data obtained from a particularly homogeneous group of males, all within a similar age group, and living in Istanbul. Although it is useful for analyzing effects of the variables considered, population selection is an important limitation. In a larger study conducted in Turkey, incidence of CHD was 0.07% (n=1407) in 2.614.089 military candidates.^[28] Similar to our study, mild congenital defects occurred in the majority of these individuals. However, level of

education was not evaluated in this large study. More extensive research needs to be conducted in Turkey, particularly in regions with poorer socioeconomic conditions. Female patients data should also be analyzed. It should be noted that, in Turkey healthy females also have some socioeconomic, religious and ethnic disadvantages in higher education. For these reasons it is difficult to generalize our results to the whole population of Turkey.

As a result, being born with CHD significantly reduces the chance of completing university education in Turkey. This negative impact on university graduation rate is independent of the severity of the disease. Disease related surgery or subsequent corrective surgery had no effect on the level of education completed. The proportion of university graduates was higher among patients who underwent surgery at a later age corresponding to the average age of elementary school graduates.

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REFERENCES

1. Deanfield J, Thaulow E, Warnes C, Webb G, Kolbel F, Hoffman A, et al. Management of grown up congenital heart disease. *Eur Heart J* 2003;24:1035-84. [\[CrossRef\]](#)
2. Warnes CA, Williams RG, Bashore TM, Child JS, Connolly HM, Dearani JA, et al. ACC/AHA 2008 guidelines for the management of adults with congenital heart disease: a report of the American College of Cardiology/American Heart Association Task Force on Practice Guidelines (Writing Committee to Develop Guidelines on the Management of Adults With Congenital Heart Disease). Developed in Collaboration With the American Society of Echocardiography, Heart Rhythm Society, International Society for Adult Congenital Heart Disease, Society for Cardiovascular Angiography and Interventions, and Society of Thoracic Surgeons. *J Am Coll Cardiol* 2008;52:e143-263. [\[CrossRef\]](#)
3. Kamphuis M, Vogels T, Ottenkamp J, Van Der Wall EE, Verloove-Vanhorick SP, Vliegen HW. Employment in adults with congenital heart disease. *Arch Pediatr Adolesc Med* 2002;156:1143-8.
4. Kokkonen J, Paavilainen T. Social adaptation of young adults with congenital heart disease. *Int J Cardiol* 1992;36:23-9.
5. Crossland DS, Jackson SP, Lyall R, Hamilton JR, Hasan A, Burn J, et al. Life insurance and mortgage application in adults with congenital heart disease. *Eur J Cardiothorac Surg* 2004;25:931-4. [\[CrossRef\]](#)
6. Moons P, Van Deyk K, De Geest S, Gewillig M, Budts W. Is

- the severity of congenital heart disease associated with the quality of life and perceived health of adult patients? *Heart* 2005;91:1193-8. [CrossRef]
7. Wray J, Sensky T. Congenital heart disease and cardiac surgery in childhood: effects on cognitive function and academic ability. *Heart* 2001;85:687-91. [CrossRef]
 8. DeMaso DR, Beardslee WR, Silbert AR, Fyler DC. Psychological functioning in children with cyanotic heart defects. *J Dev Behav Pediatr* 1990;11:289-94. [CrossRef]
 9. O'Dougherty M, Wright FS, Loewenson RB, Torres F. Cerebral dysfunction after chronic hypoxia in children. *Neurology* 1985;35:42-6. [CrossRef]
 10. Moons P, Van Deyk K, Marquet K, Raes E, De Bleser L, Budts W, et al. Individual quality of life in adults with congenital heart disease: a paradigm shift. *Eur Heart J* 2005;26:298-307. [CrossRef]
 11. Youssef NM. School adjustment of children with congenital heart disease. *Matern Child Nurs J* 1988;17:217-302.
 12. Tomita H. Adolescent congenital heart disease: quality of life in patients not undergoing intracardiac repair. *J Cardiol* 1994;24:405-9.
 13. Otterstad JE, Tjore I, Sundby P. Social function of adults with isolated ventricular septal defects. Possible negative effects of surgical repair? *Scand J Soc Med* 1986;14:15-23.
 14. Warnes CA, Liberthson R, Danielson GK, Dore A, Harris L, Hoffman JI, et al. Task force 1: the changing profile of congenital heart disease in adult life. *J Am Coll Cardiol* 2001;37:1170-5. [CrossRef]
 15. Linde LM, Adams FH, Rozansky GI. Physical and emotional aspects of congenital heart disease in children. *Am J Cardiol* 1971;27:712-3. [CrossRef]
 16. Rasof B, Linde LM, Dunn OJ. Intellectual development in children with congenital heart disease. *Child Dev* 1967;38:1043-53. [CrossRef]
 17. Green M, Levitt EE. Constriction of body image in children with congenital heart disease. *Pediatrics* 1962;29:438-41.
 18. Shillingford AJ, Wernovsky G. Academic performance and behavioral difficulties after neonatal and infant heart surgery. *Pediatr Clin North Am* 2004;51:1625-39, ix. [CrossRef]
 19. Bellinger DC, Newburger JW, Wypij D, Kuban KC, duPlessis AJ, Rappaport LA. Behaviour at eight years in children with surgically corrected transposition: The Boston Circulatory Arrest Trial. *Cardiol Young* 2009;19:86-97. [CrossRef]
 20. Gordon N. Learning disorders and delinquency. *Brain Dev* 1993;15:169-72. [CrossRef]
 21. Huntington DD, Bender WN. Adolescents with learning disabilities at risk? Emotional well-being, depression, suicide. *J Learn Disabil* 1993;26:159-66. [CrossRef]
 22. Naylor MW, Staskowski M, Kenney MC, King CA. Language disorders and learning disabilities in school-refusing adolescents. *J Am Acad Child Adolesc Psychiatry* 1994;33:1331-7. [CrossRef]
 23. Linde LM, Dunn OJ, Schireson R, Rasof B. Growth in children with congenital heart disease. *J Pediatr* 1967;70:413-9. [CrossRef]
 24. O'Dougherty M, Wright FS, Garmezzy N, Loewenson RB, Torres F. Later competence and adaptation in infants who survive severe heart defects. *Child Dev* 1983;54:1129-42. [CrossRef]
 25. Newburger JW, Silbert AR, Buckley LP, Fyler DC. Cognitive function and age at repair of transposition of the great arteries in children. *N Engl J Med* 1984;310:1495-9. [CrossRef]
 26. Wright M, Nolan T. Impact of cyanotic heart disease on school performance. *Arch Dis Child* 1994;71:64-70. [CrossRef]
 27. Fowler MG, Johnson MP, Atkinson SS. School achievement and absence in children with chronic health conditions. *J Pediatr* 1985;106:683-7. [CrossRef]
 28. Kurşaklıoğlu H, Barçın C, Kırılmaz A, Erinç K, Köse S, Sağ C, et al. Incidence of congenital heart disease in male, young adults in Turkey. [Article in Turkish] *Türk Kardiyol Dern Arş* 1998;26:529-32.
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