

## Multidisciplinary Evaluation of Heart Transplantation and Ventricular Assist Device Implantation in a Child with Autism Spectrum Disorder

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### ABSTRACT

Organ transplantation practices have witnessed tremendous advances all over the world and in Türkiye in recent years, and the pre-transplantation preparation, operation and postoperative follow-up procedures are being meticulously handled. However, there is very limited information about follow-up processes of pediatric patients with autism spectrum disorder (ASD) undergoing organ transplantation. Furthermore, it is difficult to manage the arduous and long-term care and follow-up processes in ASD cases undergoing organ transplantation. In this case report, an 11-year-old male patient with a diagnosis of ASD and attention deficit-hyperactivity disorder (ADHD) was reviewed psychiatrically for the suitability of ventricular assist device (VAD) implantation and heart transplantation, and the multidisciplinary council process was evaluated.

The council decided that the case was suitable for heart transplantation but not suitable for long-term intracorporeal device implantation due to behaviors such as plucking wounds, playing with vascular access, and being nervous about vascular access. The council stated that due to sensory hypersensitivity of the case, implantation of such a device may further increase anxiety, and involuntary damage to the device may result in personal harm. We hope that this case report will guide future endeavors to develop devices suitable for cases with ASD or other behavioral problems.

**Keywords:** Autism spectrum disorder; cardiac transplant; interdisciplinary treatment team; psychopathology; ventricular assist device

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### INTRODUCTION

The number of heart transplantations in Türkiye has been increasing steadily since 1996. Ventricular assist device (VAD) works as a bridge while patients with advanced heart failure wait for a heart transplant. VADs are mechanical pumps that support the heart and blood flow in patients with poor heart function. VADs use a hydrodynamic centrifugal pump with a short inlet cannula that is placed intracorporeally in the pericardium at the apex of the ventricle, and is connected to the external unit and batteries with the help of a cable. The cannula design and the small size of the device facilitate intrapericardial placement. Patients carry this device with them in a 30×45 cm bag with two replaceable batteries and a main box with a screen. Thus, they are no longer confined to bed and hospital dependence is reduced. Patients should be able to monitor the screen to constantly check the battery level and alarms, and this bag and the cables coming out of the bag must be constantly protected. Post-surgical anticoagulant treatment is started in patients implanted with VADs and the International Normalized Ratio (INR) is checked every week. Furthermore, patients undergo physical examination, echocardiography and psychiatric evaluations every month. All family members receive training on device functions, problem-solving methods, wound dressing, and possible complications of anticoagulant therapy (1). In addition to protecting the device, patients and families also need to watch out for situations such as accidental blows to the body and minor injuries due to possible complications of anticoagulant therapy.

### Highlights

- Multidisciplinary approach is very important in heart transplantation processes in ASD.
- Family evaluation should also be included in the heart transplantation process in ASD.
- Comorbid psychiatric disorders in ASD may affect medical intervention processes.

Individuals diagnosed with autism spectrum disorder (ASD) exhibit symptoms such as difficulty in establishing social relations, communication difficulties, and repetitive behavior patterns (2). Furthermore, it is difficult to manage complex situations such as organ transplantation encompassing arduous and long-term care and follow-up processes in ASD cases with severe symptoms (3). Even though organ transplantation procedures have shown great advances in recent years, there is still limited information about the care and follow-up processes of pediatric patients with ASD.

In pediatric and adolescent cases of VAD implantation and heart transplantation, it is very important to ensure that the cases are psychiatrically evaluated in the preoperative and postoperative period (4,5). In this case report, an 11-year-old male patient with a diagnosis of ASD and attention deficit hyperactivity disorder (ADHD), who was hospitalized with the diagnosis of dilated cardiomyopathy and whose preparations were completed for inclusion in the heart transplant list, was reviewed psychiatrically for the suitability of VAD implantation and heart transplantation and the multidisciplinary council process was evaluated. Additionally, the objective of this case report is to create an overview of how psychiatric conditions affect medical treatment, rather than to discuss medical parameters, and to provide guidance for medical device manufacturers in relation to such cases.

## CASE REPORT

An 11-year-old male patient was born with the diagnoses of double outlet right ventricle (DORV), left ventricular outflow tract (LVOT) stenosis, ventricular septal defect (VSD), and subaortic ridge. The patient was operated for VSD closure and total correction at the age of 4.5 months, and was reoperated for subaortic ridge at the age of 4 years. The patient had been followed-up by a pediatric cardiologist since birth. In August 2021, the patient applied to a state hospital with the complaints of vomiting and abdominal swelling for 3 weeks.

In the physical examination of the patient, hepatomegaly, abdominal ascites, and pretibial edema +1 were detected. The patient's cardiac examination revealed tachycardia, S3 gallop rhythm, and 4/6 mitral insufficiency murmur. Echocardiography revealed an ejection fraction of 10%, increased left ventricular end diastolic measurement, and moderate mitral regurgitation.

The case was referred to hospital with the pre-diagnosis of dilated cardiomyopathy. The diagnosis was confirmed and the patient was admitted to the Pediatric Cardiology unit. Considering the indication for cardiac transplantation during the hospitalization period, the patient was consulted to child and adolescent psychiatry for suitability for ventricular assist device (VAD) implantation and heart transplantation, and psychiatric evaluation was performed.

The patient was born 2.450 grams with normal spontaneous vaginal delivery at 36 weeks of gestation. Five days after birth, the patient was hospitalized for two days due to pathological jaundice. The patient was operated at 4.5 months (VSD closure, total correction) and 4 years (sub aortic ridge rejection) of age due to DORV. The mother was 36 years old; the father was 37 years old, and both were medically and psychiatrically healthy. There was no known psychiatric illness in the family.

At the age of 2 years and 9 months, the patient was diagnosed with ASD and followed-up by child psychiatry. After ASD diagnosis, the patient started to receive special education support and sports training. Attention deficit-hyperactivity disorder comorbidity was noted in patient files. Interviews with the mother and the special education teacher revealed that the patient learned to read and write in the 2nd grade, was indifferent to his peers and lived in a world of his own, was able to take care of himself, ate his own food, had anger management issues until two years ago, was very active especially in the preschool period, became calmer and more harmonious in later years, and showed no harmful behavior. It was learned that the patient used 2–8 mg/day aripiprazole for 4–5 years and received 20 mg/day methylphenidate treatment for 3 months before hospitalization, and purposeless motor behaviors decreased with treatment.

Psychiatric evaluation concluded that the patient's physical appearance was compatible with his age, the patient avoided eye contact, lived in a world of his own, had extremely poor skills in initiating and maintaining communication, and repeated certain words in the form of echolalia and palilalia, and formed sentences of 3–4 words. The patient was not able to take standard tests due to his current medical and psychiatric condition; however, considering that the patient learned to read and write in the second grade, one year later than his peers, the patient was clinically evaluated as having borderline intellectual functioning. The mother reported that the patient slept regularly, but suffered from night wakings due to pain, lost appetite due to his current medical condition, and exhibited symptoms such as swiveling, tactile and auditory hypersensitivity, confusing pronouns, not being interested in toys, and obsessively watching things (sand, stone, etc.) fall but the family did not experience problems complicating daily life for the past two years despite the patient exhibiting purposeless motor behaviors.

Childhood Autism Rating Scale was administered to the patient by a child and adolescent psychiatrist, and the clinical classification was made as mild to moderate autism with a total of 31 points (6). The DSM-IV-Based Screening and Evaluation Scale for Disruptive Behavior Disorders, filled out by the mother, revealed a score of 7/16 for inattention, 2/8 for hyperactivity/impulsivity, 0/0 for opposition/defiance, and 0/0 for conduct disorder (7). Based on these findings, the patient met the criteria for ASD and ADHD according to The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (2).

After all medical and psychiatric evaluations are completed, patients who are planned for VAD implantation and included in the waiting list for heart transplantation are discussed by the team leaders at the council meeting held every Wednesday, and the final decision is made by the council, which consists of cardiologist, pediatric cardiologist, cardiovascular surgeon, pulmonologist, pediatric pulmonologist, infectious disease physician, microbiologist, nephrologist, pathologist, psychiatrist and child and adolescent psychiatrist. Before the council meeting, pediatric patients with end-stage heart failure are evaluated by a pediatric cardiologist, a cardiovascular surgeon, and a child and adolescent psychiatrist.

For this case, the council decided that the patient was suitable for heart transplantation but not suitable for long-term intracorporeal device implantation due to behaviors exhibited during hospitalization such as plucking wounds, playing with vascular access, and being nervous about vascular access. The council further stated that due to sensory hypersensitivity of the case, implantation of such a device may further increase anxiety, and involuntary damage to the device may result in personal harm. In this case report, written informed consent was obtained from the patient and the patient's parents according to Declaration of Helsinki.

## DISCUSSION

There is very limited information in the literature on heart transplantation and VAD implantation in children with autism, and it is emphasized that patients with autism require multidisciplinary care after VAD implantation and in the postoperative period after heart transplantation (3). Therefore, more frequent follow-ups in cooperation with a child psychiatrist and nurse were planned for the case after a possible transplantation. Although ASD does not create a significant contraindication for VAD implantation, psychiatric evaluation concluded that the patient was unsuitable for VAD implantation considering the current psychiatric condition of the patient (patient could fail to show necessary care and a possible self-destructive situation could be life-threatening) and family's concerns.

There is also limited information in the literature on VAD implantation in adult patients with autism or intellectual disability. Although the absence of intellectual disability is considered a requirement in the selection of patients for VAD implantation, a patient with mild intellectual disability was implanted with VAD because there was no additional behavioral problem that could pose a risk for a possible self-destructive incident or emotion regulation problems, and since the patient understood well the requirements of device use (8,9).

In terms of heart transplantation, no psychiatric contraindications were found in the presented case thanks to factors that could facilitate the process, such as the absence of intellectual disability, good environmental support, continued special education and sports, benefiting from methylphenidate treatment, and supporting factors such as body integrity remaining the same and not having to carry an external device that needs protection. Necessary preparation steps for transplantation were completed so that the patient would be included in the transplant list when necessary.

In conclusion, even though this case is suitable for heart transplantation, there are medical difficulties due to the inability to use a VAD, such as the inability to perform bridge treatment with a VAD in the event of advanced heart failure, prolonged hospital stay, and the need to resort to intravenous inotropic treatments that can be administered in the hospital. In addition, the long-term hospitalization of the patient may increase noncompliance to treatment combined with the current psychiatric condition of the patient. The fact that bridge treatment cannot be performed with VAD until a suitable transplant is found reduces the patient's chance of survival compared to cases that can use a VAD. Considering all these difficulties, we hope that this case report will guide future endeavors to develop devices suitable for cases with ASD or other behavioral problems.

**Informed Consent:** Written informed consent was obtained from the patient and the patient's parents.

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