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Psychiatric aspects of children in the transplantation process: 6-year outcomes from a tertiary hospital

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ABSTRACT

Objective: Pediatric patients undergoing transplantation are at increased risk for a variety of psychiatric problems. The aim of this study was to analyse the data of children and adolescents referred to the child and adolescent psychiatry unit of a tertiary hospital and who were in the process of transplantation.

Material and Methods: This retrospective observational study, planned using the hospital information system and patient records, included clinical data over a 6-year period. Patients were assessed according to the Diagnostic and Statistical Manual of Mental Disorders, 5th edition.

Results: This study included the data of 64 patients (n= 30, 46.9% girls) in the transplantation process. Of the patients, 46 (71.9%) were undergoing kidney transplantation, 13 (20.3%) bone marrow transplantation, two (3.1%) liver transplantation, two (3.1%) lung transplantation, and one (1.6%) heart transplantation. The duration of pre-transplant illness was approximately 5.21±4.17 years. The most common reason for admission to child psychiatry unit was pre-transplant psychiatric and intelligence assessment. Thirty-two (50%) patients were diagnosed with any mental illness. The most common diagnoses were depression and adjustment disorder. No association was found between the duration of pre-transplant illness and the mean psychiatric diagnosis (r= -0.101, p= 0.603).

Conclusion: The data from this study will help to guide mental health and psychosocial care in this population. Prospective longitudinal studies of children are needed to determine optimal psychiatric assessment.

Keywords: Adjustment disorder, bone marrow transplant, children, depressive disorder, kidney transplant

INTRODUCTION

Chronic illnesses and transplantation processes in children and adolescents are complex and influence the individual's functioning in terms of family, school and peer relationships. Patients are affected by many mental health problems such as depression, anxiety, attention deficit hyperactivity disorder and have more developmental and neurocognitive delays compared to healthy controls. Addressing these concerns is associated with positive transplant outcomes (1-3).

Patients with chronic kidney illness have a reduced quality of life and a higher risk of hospitalisation, heart problems and death (4). Although kidney transplantation is difficult for these patients, it is better than hemodialysis and peritoneal dialysis in terms of quality of life. In addition, kidney transplant patients have lower levels of anxiety and depression than haemodialysis and peritoneal dialysis patients (5). There are studies in the literature on children undergoing kidney, bone marrow and heart transplantation, with kidney transplantation being the most common area of research (1-3,6-9). Studies have evaluated pre-transplant and post-transplant processes, and some pre-transplant factors, including the patient's psychiatric history, have been associated with poorer outcomes. The presence of psychiatric factors and psychosocial problems such as anxiety/depression, low self-esteem, social and peer difficulties, emotional and behavioural problems have also been associated with an increased risk of non-adherence. Notably, several aspects of family functioning, including parental psychopathology, also place patients at increased risk for psychiatric and post-transplant concerns. In particular,

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duration of pre-transplant illness, lower intelligence scores and learning disabilities, age, prolonged school absence, attention and neurocognitive difficulties may increase the risk of mental health problems (1-3). Intelligence is also an important factor and may affect the transplant process, but intellectual disability alone is not a contraindication to transplantation (10). Another study of children who received a kidney transplant reported that these children had more emotional and behavioural problems and a lower quality of life than the healthy control group (7). Psychosocial support should be provided after transplantation. Monitoring patients to determine the level of risk and intervention needed to address neurocognitive factors is important to promote academic functioning and success, adherence to treatment, and overall functioning (6,7).

Similar processes occur in heart transplant patients, suggesting the need for pre- and post-transplant psychiatric assessment and the importance of a multidisciplinary approach and inter-institutional collaboration in the child and adolescent age group (8). In bone marrow transplant patients, children often describe fears of life-threatening illness, along with fears of illness and death, feelings of being a burden to the family, low self-esteem, helplessness and vulnerability. During transplantation, the main problems are anxiety, depression, overdependence and regression, along with anger, reduced tolerance to procedures and periodic refusal to cooperate. Children also experience high levels of anxiety due to fear of procedures and express concern when complications occur; as they become more seriously ill, they often ask not to be left alone. Despite this, children suffering from the stress of a bone marrow transplant have fewer and less severe overt psychiatric disorders than might be expected. Adjustment disorder with depressed mood, separation anxiety disorder and major depressive disorder make up the majority of cases (9).

This study aimed to evaluate the sociodemographic and clinical characteristics, psychiatric diagnoses, and follow-up processes of pediatric patients referred to child and adolescent psychiatry during kidney, bone marrow, heart, liver, or lung transplantation.

MATERIALS and METHODS

This retrospective observational study was conducted at Marmara University Pendik Research and Training Hospital, a tertiary care center. Data were collected through the hospital information management system and patient medical records. The study sample included pediatric patients who were referred to the Child and Adolescent Psychiatry Clinic for consultation from the organ transplantation unit, bone marrow transplantation unit, or from the pediatric nephrology and hematology outpatient clinics within the same institution. Our clinic is an outpatient unit, we do not have an inpatient unit. Kidney and bone marrow transplants are performed in our hospital; patients in the process of lung, heart and liver transplantation are referred to our clinic from other hospitals for child and adolescent psychiatric assessment as consultations. The data in this retrospective study includes the period between 2018 and the first half of 2024. Psychiatric interviews were conducted in the services where the patients were hospitalised. Other interviews were conducted in outpatient clinics with patients who were admitted as outpatients. Interviews with foreign patients were conducted with the help of an interpreter. In our outpatient clinic, patients are assessed using the Schedule for Affective Disorders and Schizophrenia for School-Age Children-Present and Lifetime Version-Turkish Adaptation (K-SADS-PL). The K-SADS-PL is a semi-structured diagnostic interview developed by Kaufman et al. (11). The Turkish version has undergone validity and reliability studies by Gökler et al. (12).

Patients' psychiatric disorders were diagnosed according to the Diagnostic and Statistical Manual of Mental Disorders, 5th edition. Patients with suspected cognitive problems were assessed using the Wechsler Intelligence Scale for Children-Revised (WISCR). According to the test results, a total intelligence section score of 90 and above was classified as normal, 70-89 as borderline, and 55-70 as mild intellectual disability. Since this study was a retrospective study, no consent was obtained, but necessary permissions were obtained and patient privacy was taken into consideration. Sociodemographic form is a form created by the researchers. Participants' age and sex, school, psychiatric history, family psychiatric history, intelligence level, time and reason for consultation, pre-transplant diagnoses, psychiatric diagnoses, psychopharmacological treatments and information about their follow-up were recorded.

Statistical Analysis

The analysis of the data was conducted utilising the IBM Statistical Package for the Social Sciences, version 20.0 (SPSS Inc., Armonk, NY, IBM Corp., USA). Sociodemographic data, primary childhood illness, transplanted organ/tissue, duration of illness, psychiatric diagnoses and treatment modality were analysed using descriptive statistics. Descriptive statistics, expressed as mean and standard deviation, were used to analyse the study data. The correlation between the duration of illness in children and the mean psychiatric disorders was examined using Spearman correlation analysis. A $p<0.050$ was considered significant.

RESULTS

The study sample consisted of 64 patients, 30 of whom were girls (46.9%). Two patients were Syrian. The mean age of the patients was 12.70±3.41 years. The mean number of siblings of the patients was 2.38±0.80. Thirty-two (50%) patients were able to attend school, while the other half could not attend school due to their illness. Sixteen (25%) patients had a history of psychiatric outpatient treatment. Previous psychiatric

Table I: Primary pediatric diagnosis (with ICD-10 codes) for transplant

Transplated organ, tissue	Disease-ICD 10 codes	Number of patients*
Kidney	Chronic kidney disease (N18.1-9), Kidney transplant status (Z94.0), Malignant neoplasm of kidney (C64), Nephrotic syndrome (N04)	46 (71.9)
Bone marrow	Neutropenia (D70) Severe combined immunodeficiency (D81) Malignant neoplasm of unspecified part of adrenal gland (C74.9) Hodgkin lymphoma (C81) Leukemia (C91, C94, C95) Aplastic anemia (D61)	13 (20.3)
Liver	Fibrosis and cirrhosis of liver (K74) Metabolic disorders (E70-88)	2 (3.1)
Lung	Cystic fibrosis (E84) Primary ciliary dyskinesia/Cartagener syndrome	2 (3.1)
Heart	Cardiomyopathy (I42)	1 (1.6)

***:** *n(%)*

Table II: The reasons for admissions/referrals, psychiatric diagnoses distribution and intelligence level of sample

The reasons for admissions/referrals (n)	64
Intelligence assessment	13
Depressive symptoms	6
Anxiety	6
Hyperactivity-attention problems	10
Pre-transplant psychiatric assessment	42
Noncompliance with treatment/medication	11
Food refusal	2
Presence of psychiatric diagnosis*	32 (5)
Number of diagnoses †	2.25±1.09
Presence of major depresive disorder (F32)*	12 (37.5)
Presence of adjustment disorder (F43)*	12 (37.5)
Presence of attention deficit hyperactivity disorder (F90)*	7 (21.9)
Presence of dyslexia (F81)*	1 (3.1)
Intelligence level*	57
Normal intelligence	44 (68.8)
Intellectual disability (F70)	9 (14.1)
Borderline mental functioning	4 (6.3)

***:** *n(%)*, **†:** *mean±SD*

diagnoses were; three (4.7%) patients had depression, two (3.1%) patients had adjustment disorder, three (4.7%) patients had attention deficit hyperactivity disorder, eight (10.9%) patients had mild intellectual disability and one (1.6%) patient had dyslexia. Patients diagnosed with intellectual disability and dyslexia were in special education. Twenty-three patients (35.9%) had a history of mental illness in one of their parents.

In the sample, 46 (71.9%) patients were in the process of kidney transplantation, 13 (20.3%) patients were in the process of bone marrow transplantation, two (3.1%) patients were in the process of liver transplantation, two (3.1%) patients were in the process of lung transplantation, and one (1.6%) patient was in the process of heart transplantation. The primary pediatric diagnosis (with ICD-10 codes) for transplantation is shown in Table I.

Of the patients, 44 (68.8%) had normal intelligence (intelligence score according to WISCR test; 90-110), four (6.3%) had borderline mental functioning (70-89) and nine (14.1%) had intellectual disability (mild level-55-70). For seven patients, no record of intelligence level could be found in the files or in the system. There were no patients with moderate or severe intellectual disability in the sample. Looking at the distribution of patients per year, 32 (50) patients were assessed in 2018, 14 in 2019, 13 in 2020 and eight patients per year between 2021-2024.

Forty-two (65.6%) of the patients were referred to our clinic before transplantation, six (9.4%) were evaluated after transplantation and 16 (25%) were evaluated both before and after transplantation. Patients were evaluated 2.61±2.03 times in our outpatient clinic. Thirty-two (50%) patients (16 of them were girls) were diagnosed with any mental illness, while 32 (50%) did not meet the diagnostic criteria for any mental illness. The patients who were diagnosed had an average of 2.25±1.09 diagnoses. The reasons for admission/referral and the distribution of diagnoses (with ICD-10 codes) are shown in Table II.

Psychopharmacological treatment was planned for 16 (50%) patients with a psychiatric diagnosis. As the transplant unit did not consider the use of psychotropic medications to be appropriate due to the patients' chronic conditions (due to drug interactions and side effects such as bleeding, immunosuppression related to the primary diagnosis), approval was not given. The most commonly prescribed treatment was serotonin reuptake blockers in 12 patients (75%). Twenty-one of the 32 patients (65.2%) were followed up in our clinic. The duration of pre-transplant illness was approximately 5.21±4.17 years. No association was found between the duration of pre-transplant illness and the mean psychiatric diagnosis (r= -0.101, p= 0.603).

DISCUSSION

According to the results of our study, many psychiatric disorders can be diagnosed in children during the transplantation process. Psychiatric disorders can influence pre-transplantation and post-transplantation outcomes. It is important to evaluate patients' mental health before and after transplantation.

Half of the children in our sample group were unable to attend school during the period they were admitted to our clinic. The school environment contributes to the academic, social and personal development of children and adolescents, and absence from school has a negative effect on children and adolescents with any chronic illness (13). It is important that patients continue their education at home or in hospital schools during the early post-transplant period. The implementation of individualised education plans and other school services, including computerised training programmes, should be considered.

Having a mental illness prior to transplant is a risk factor for stressful situations that may develop during and after the transplant process (14). Untreated psychiatric morbidities may worsen and reduce medical compliance after transplantation, which may lead to rejection of the transplanted organ or tissue. In our sample, 25% of patients had a history of outpatient psychiatric treatment. Conversely, anxiety, depression and post-traumatic stress disorder have been reported in parents of children undergoing transplantation. Parents' mental health issues can influence their children's mental well-being at all stages of the transplant process (7,15). One third of our sample group had a parent who was diagnosed with a mental illness. We could not obtain data on whether the diagnosis occurred before or after transplantation. Nevertheless, parents should receive psychological support, such as family or cognitive behavioural therapy.

The patients referred to our clinic did not have a moderate or severe intellectual disability. They may not have been on the waiting list as potential recipients because they were unable to adapt to the post-transplant process. The relationship between intellectual disability and organ transplantation in children is multifaceted, encompassing clinical, ethical, and policy dimensions. Historically, children with intellectual disability have faced significant barriers to accessing life-saving transplants, often due to misconceptions about their quality of life and potential outcomes. However, recent studies and policy shifts are challenging these assumptions and advocating for more equitable treatment. A study found that children with intellectual disability had similar graft survival rates and lower rates of acute rejection compared to those without intellectual disability (10). Another study reported that children with intellectual disability had comparable short-term graft and patient survival rates to those without intellectual disability (11). Additionally, a study conducted in Japan suggests that kidney transplantation is not contraindicated in patients with intellectual disabilities. However, it was also emphasised that researchers cannot determine which patients are unsuitable for transplantation (12). Further multidisciplinary and prospective studies are needed to enable such predictions to be made. However, it is clear that children with intellectual disabilities and their families require additional support throughout this process. Intellectual disability can make the process more stressful for children and may lead to more non-compliance and behavioural problems. If intellectual disability has a genetic aspect, their parents may also be affected.

Half of our sample group had a diagnosis of mental illness. Consistent with other studies, the most common diagnoses were depression, adjustment disorder and intellectual disability (2,3,6,18). Studies have reported that the rate of having a psychiatric diagnosis during the transplant process is around 60% (18,19). In our study, half of our sample had a psychiatric diagnosis. Major depression and adjustment disorder are the most common psychiatric diagnoses among hospitalised patients have been associated with an increased incidence of suicide attempts and completions (20). The presence of comorbid psychiatric disorders in the post-transplant period is an important risk factor for graft rejection. Non-compliance with treatment/medication was also the reason for referral in some patients. Psychiatric disorders may contribute to non-compliance with treatment/medication. Patients with psychiatric disorders already have a low rate of medication compliance and an increased health risk (21). Furthermore, psychopharmacological treatment could not be applied to all patients with mental illness. Drug interactions and side effects such as bleeding or immunosuppression caused by primary pediatric illnesses were evaluated interclinically. For this special group, cognitive behavioural therapy, dialectical behavioural therapy and mindfulness-based therapies should be considered as an alternative to psychopharmacological treatments. Cognitive behavioural therapy is one of the most evidence-based treatments for anxiety and depression in children who are in the transplant process. It helps children cope with medical anxiety, anticipatory fear, and treatment-related stress, enhances adherence to complex post-transplant regimens by addressing maladaptive thoughts and behaviors, builds coping skills for pain, uncertainty, and hospitalization (22). Dialectical behavioural therapy may be effective in reducing self-harming behaviors, emotional volatility, and non-adherence and offer structured modules on distress tolerance, emotion regulation, mindfulness, and interpersonal effectiveness- all critical in managing post-transplant stress (23). Mindfulness-based therapies reduce preoperative anxiety and postoperative stress, improves pain management, sleep, and emotional well-being (24).

This study has important limitations. Firstly, the data were retrospective. As the study included data from a single centre, the sample size was small. Patients were not reassessed for the study, and self-report psychiatric scales were not used. There

was also a lack of socio-demographic information. Further statistical analysis could not be performed using the available data. Information on post-transplant processes and follow-up data on graft function could not be obtained.

CONCLUSION

Studies have shown that interdisciplinary interventions involving psychiatrists, physicians, nurses, dieticians, and social workers in the transplant population are associated with improved outcomes, including delay in ilness progression, improved patient education and preparedness, and reduced mortality (25). However, clinical data from large transplant centres are limited. This study includes data from a small sample, therefore the results cannot be generalised, but the results of this study can contribute to the literature, consequently it includes data from a 6-year experience.

Ethics committee approval

This study was conducted in accordance with the Helsinki Declaration Principles. Ethical approval was obtained from the Ethics Committee of the Medical Faculty of Marmara University (09.02.2024/178).

Contribution of the authors

All the authors made substantial contributions to conception and design, and/or acquisition of data, and/or analysis and interpretation of data; participated in drafting the article and revising it; and gave final approval of the submitted version. Ünver H and Perdahlı Fiş N: has the study conception, designed the study; Ünver H: has drafting of the manuscript; performed analyses and interpretation of data, , Bırık HE: involved in the acquisition of data and made critical revisions. All authors participated in the interpretation of data and contributed significant intellectual content to the article.

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Conflict of interest

The authors declare that there is no conflict of interest.

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