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Evaluation of Stigma Problems Experienced after Immune Transplantation According to Donor Types

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Abstract: Aim: Liver failure, both acute and chronic, is a significant issue in Turkey and worldwide, leading to serious consequences and often necessitating organ transplantation as a critical treatment step. This process, however, frequently results in patients having to navigate life with disabilities. In this study, the societal stigmatization experienced by liver transplant patients and the challenges it brings were evaluated. Metods: This prospective study was conducted on liver transplant patients followed in a tertiary university hospital. Demographic data, stigmatization experiences, and the Rosenberg Self-Esteem Scale were utilized, and the findings were recorded. Results: The study included 150 participants, 35.3% of whom were female, with a mean age of 52.26 ± 14.83 years. Of these, 48.7% had undergone cadaveric transplantation, while 51.3% had received living donor transplants. Among the participants, 77.3% had high self-esteem, while 22.7% had moderate self-esteem. No differences were observed in the responses to questions on stigmatization and bullying based on transplant type or self-esteem levels. Conclusion: The differences in donor sources and the self-esteem of individuals did not have an impact on the stigmatization experienced by the patients.

Keywords: Liver transplantation, Stigma, Rosenberg Self-esteem, Bullying.

INTRODUCTION

Liver transplantation, commonly used for the treatment of liver failure caused by cirrhosis and decompensated liver pathologies, is a therapeutic method for end-stage liver diseases in both acute and chronic conditions [Dababneh, Y. *et al*., 2024; Schnitzler, M.A. *et al*., 2005]. In Turkey, 7,984 liver transplants were performed in 2017 [Vakfı, T.O.N, 2018].

Stigma, which manifests through situations such as the humiliation of individuals, the grouping of social structures in modern society, and the exclusion of individuals, can occur for various reasons within society. The stigmatization of disabled individuals is a multifaceted issue that affects various aspects of their lives, including social interactions, education, and overall quality of life. Research highlights that physically disabled children in northwest Ethiopia face bullying, social exclusion, and humiliation, significantly impacting their emotional well-being and educational activities [Adugna, M. B. *et al*., 2024]. This stigma is not limited to physical disabilities; individuals with mental disabilities also experience stigmatization, which can be alleviated through interventions such as music therapy. Music therapy has been shown to help overcome stigma by improving quality of life and expanding the professional standards of social work [Baranauskienė, I. *et al*., 2024]. In the realm of social media, autistic individuals use both individual and collective stigma management strategies to enhance their online experiences, which are crucial for their social participation [Koteyko, N. *et al*., 2024].

Organ transplants present a complex situation for adults, often leading to changes in life and the emergence of disability due to post-operative care and treatment processes [Denning, L. A. *et al*., 2021]. Liver transplantation, in particular, represents a form of disability. This study evaluates the social stigmatization experienced by these patients and the challenges that arise from it.

MATERIALS AND METOHS

This study was conducted on liver transplant patients followed up in the Internal Medicine Department of a tertiary university hospital after obtaining ethical approval. The demographic data, transplantation histories, experiences of stigmatization, and results from the application of the Rosenberg Self-Esteem Scale (RSES) of patients who underwent liver transplantation and were under follow-up at the hospital were recorded. The collected data were analyzed.

The study included individuals over the age of 18 who had undergone liver transplantation, while those who had previously undergone transplantation but were lost to follow-up, those who did not provide consent to participate in the study, those who did not complete the data form, and those who lacked the ability to provide

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appropriate responses to the questions were excluded from the study.

Sample Size

In a liver disease study conducted by Devarbhavi and colleagues, the global prevalence of liver disease was determined to be 4% [Devarbhavi, H. *et al*., 2023]. Using this prevalence value, a simple sample size calculation with a 95% confidence interval and a 5% margin of error indicated that the minimum required sample size was 60 participants. In our study, after the analysis, we reached 155 patients followed up in our clinic, and the study was conducted with the participation of 150 of these patients.

Rosenberg Self-Esteem Scale

The scale, developed by Rosenberg in 1965, measures an individual's self-esteem [Rosenberg, M. *et al*., 1965]. The Rosenberg Self-Esteem Scale consists of 10 questions and is scored using a four-point response scale. As the score increases on this scale, self-esteem decreases. It is determined that scores between 0-1 indicate high self-esteem, scores between 2-4 indicate moderate self-esteem, and scores between 5-6 indicate low self-esteem [Çuharoğlu, F. *et al*., 1986].

Scoring: 1; c=0.17, d=0.34, 2; c=0.16, d=0.33, 3; a=0.17, b=0.33, 4; c=0.25, d=0.5, 5; c=0.25, d=0.5, 6; c=0.5, d=1, 7; c=0.5, d=1, 8; b=0.5, a=1, 9; a=0.5, b=0.25, 10; a=0.5, b=0.25.

Statistical Analysis

After the collected data were compiled into a data form, the analysis was performed using SPSS version 27 (IBM Corp). Categorical data were described as percentages and frequencies. The Chi-square test was used to analyze the relationships between categorical data, and the Monte Carlo exact test was performed. Numerical data were analyzed for distribution, and the mean ± SD was used to describe normally distributed numerical data. In this study, findings with a p-value of less than 0.05 were considered statistically significant.

RESULTS

A total of 150 participants were included in the study, 35.3% of whom were women, with an average age distribution of 52.26±14.83 years. Of the participants, 48.7% received transplants from cadaveric donors, while 51.3% received transplants from living donors. The most common reason for transplantation was cryptogenic in 36% of cases. According to the Rosenberg Self-Esteem Scale (RSES), 77.3% of the participants had high self-esteem, while 22.7% had moderate self-esteem (Table 1).

Table 1: Distribution of demographic data of participants

Spesification	Value
Gender, Female (n, %)	53 (35,3)
Age (mean±SD)	52,26±14,83
Transplantation Type (n, %)	
Cadaver	73 (48,7)
Live	77 (51,3)
Etiology (n, %)	
Cryptogenic	54 (36)
Infections	49 (32,7)
Autoimmune	19 (12,7)
Alcohol	16 (10,7)
Other	12 (8)
Rosenberg Self-Esteem Scale score (mean±SD)	0,77±0,61
High (n,%)	116 (77,3)
Middle (n, %)	34 (22,7)
Low (n, %)	0

The participants were asked 11 short questions about their experiences. The distribution of responses to these questions is presented in Table 2. Participants were classified according to the type of transplantation and self-esteem categories based on the RSES scores. The responses to questions investigating the stigmatization and bullying experienced by participants were compared. No significant differences were found in the responses to the questions between those who received cadaveric or living donor transplants. Similarly, no significant differences were observed between participants with high self-esteem and

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those with moderate self-esteem, as determined by the RSES (Table 3).

Table 2: Participants' responses to questions about stigma and bullying

	Questions	N (%)
Q1	I am hesitant to tell people around me that I had a liver transplant.	9 (6,0)
Q2	I am hesitant to tell people around me that I had a liver transplant.	44 (29,3)
Q3	I feel uncomfortable in public because of my Liver Transplant.	25 (16,7)
Q4	Because of my Liver Transplant, I avoid social activities.	50 (33,3)
Q5	I think you are being discriminated against at work or school because of your Liver Transplant.	24 (16,0)
Q6	I feel uncomfortable talking about Liver Transplant.	13 (8,7)
Q7	I feel like people treat you differently when they find out you have had a Liver Transplant.	55 (36,7)
Q8	Because of my Liver Transplant, I avoid spending time with friends or family.	18 (12,0)
Q9	I think you are having problems in your partner relationships because of the Liver Transplant.	23 (15,3)
Q10	I think you are having problems in your sexual relationships because of the Liver Transplant.	32 (21,3)
Q11	When you need to take transplant medications, I keep this a secret from those around you.	4 (2,7)

Table 3: Comparison of participants' responses to stigma and bullying questions according to transplantation sources and RSS categories

	Transplantation Type			Rosenberg Self-Esteem Scale		
Questions	Cadaver (n=73)	Live (n=77)	p-Value	High (n=116)	Middle (n=34)	p-Value
Q1	8 (8,2)	3 (3,9)	0,150	6 (5,2)	3 (8,8)	0,214
Q2	25 (34,2)	19 (24,7)	0,063	31 (26,7)	13 (38,2)	0,072
Q3	13 (17,8)	12 (15,6)	0,162	19 (16,4)	6 (17,6)	0,199
Q4	21 (28,8)	29 (37,7)	0,071	37 (31,9)	13 (38,2)	0,127
Q5	12 (16,4)	12 (15,6)	0,174	18 (15,5)	6 (17,6)	0,195
Q6	8 (11)	5 (6,5)	0,145	8 (6,9)	5 (14,7)	0,097
Q7	25 (34,2)	3 (39,0)	0,113	41 (35,3)	14 (41,2)	0,131
Q8	7 (9,6)	11 (14,3)	0,136	14 (12,1)	4 (11,8)	0,235
Q9	13 (17,8)	10 (13,0)	0,129	17 (14,7)	6 (17,6)	0,187
Q10	19 (26,0)	13 (16,9)	0,063	26 (22,4)	6 (17,6)	0,164
Q11	3 (4,1)	1 (1,3)	0,236	2 (1,7)	2 (5,9)	0,185

Among patients who received cadaveric transplants, 75.3% had high self-esteem, while 24.7% had moderate self-esteem. In contrast, 79.2% of patients who received living donor transplants had high self-esteem, and 20.8% had moderate self-esteem. No significant relationship was found between the source of transplantation and self-esteem (p=0.132).

DISCUSSIONS

Disability is a widespread condition affecting a large portion of the global population. It is estimated that 15% of the world's population lives with some form of disability, with 2-4% experiencing functional difficulties [WHO, 2011]. Stigmatization associated with disability is a prevalent issue that affects disabled individuals in various socio-cultural contexts, impacting their social participation, emotional well-being, and quality of life. In Ethiopia, physically disabled children experience bullying, social exclusion, and humiliation, significantly affecting their education and social activities, highlighting the need for inclusive education policies and disability advocacy [Adugna, M. B. *et al*., 2024]. In our study, we aimed to identify the factors influencing stigmatization and bullying experienced by individuals after developing a disability following liver transplantation. There are two primary sources of transplantation: living donors and

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cadaveric donors. Our study found no significant difference in the stigmatization experiences between individuals who underwent transplants from different sources.

The organ transplantation process is associated with various psychological effects. Whether the donors are cadaveric or living, both donors and recipients may face complex psychological challenges, such as depression and anxiety. These difficulties may be exacerbated by factors such as the complex post-surgical recovery and poor health outcomes in recipients, underscoring the need for comprehensive psychosocial support and long-term follow-up for donors [Ong, J. Q. L. *et al*., 2021]. Additionally, living donors may face financial burdens and stress, which further contribute to psychological distress, emphasizing the importance of enhanced donor care and support systems [Pan, X.-H. *et al*., 2021].

Stigmatization in transplant patients is a multifaceted issue that can significantly affect their mental health and quality of life. Studies show that patients undergoing solid organ transplants, such as liver, heart, or lung transplants, often experience significant mental distress, which is closely linked to their health-related quality of life [Baranyi, A. *et al*., 2013]. This distress can be exacerbated by stigmatization, a common experience among patients with chronic conditions. For example, patients with liver disease, particularly those with cirrhosis, report higher levels of perceived stigmatization, which affects their self-perception and their willingness to disclose their condition to others [Østberg, N. *et al*., 2023]. This stigmatization can lead to feelings of rejection and social isolation, similar to the experiences of patients with psoriasis, where societal views and behaviors contribute to the sense of stigma, ultimately affecting their social status and quality of life [Zhang, H. *et al*., 2021]. One of the factors influencing transplant patients is the etiological structure and the source of the donor. In our study, there was no significant difference in the distribution of responses to questions comparing the stigmatization and bullying experienced by patients based on their donor source. Psychological effects may occur at every stage of the transplantation process, but as our study shows, the donor being cadaveric or living has no significant effect on stigmatization or self-esteem in patients.

Self-esteem plays a crucial role in the lives of organ transplant patients, affecting their quality of life and psychological well-being. Research indicates that self-esteem is closely linked to quality of life in patients who have undergone organ transplants, such as liver or kidney transplants. For example, a study conducted on patients over the age of 60 who had undergone liver transplants more than 10 years ago found that self-esteem significantly impacted their perceived quality of life, along with factors such as gender, diagnosis, and social environment [Jover-Aguilar, M. *et al*., 2020]. Moreover, self-awareness and emotional awareness are vital for transplant teams, as both donors and recipients navigate the complex emotional landscape of organ donation, which can indirectly affect their self-confidence [Paula, I. *et al*., 2017]. Various factors can influence self-esteem, including sexual problems [Abdelhamid, E. A. *et al*., 2024], obesity and body image issues [Uzdil, Z. *et al*., 2024], and conditions like HIV that are associated with stigmatization and can impact individuals' social roles and self-esteem [Huang, H. *et al*., 2024]. In our study, we compared the relationship between the participants' self-esteem and their experiences of stigmatization. No significant difference was found in the responses to questions assessing stigmatization among individuals with high and moderate self-esteem.

Social support and psychological health are important factors that influence individuals' treatment processes. Diseases that lead to disability often result in stigmatization, stress disorders, and anxiety. This study examined the relationship between the differences in individuals and the stigmatization they experienced after developing a disability due to liver transplantation. Whether the transplantation was from living or cadaveric donors had no significant effect on individuals' self-esteem or experiences of stigmatization.

LIMITATIONS

Our study is descriptive in nature, comparing the transplantation characteristics and stigmatization experiences of individuals post-transplant. This approach presents certain limitations. Conducting the study with a follow-up process, assessing the effects of stigma and self-esteem both before and after transplantation, could provide further insight into the impact of donor type, as well as the effects of transplantation on stigmatization and self-esteem.

CONCLUSIONS

The difference in donor sources does not affect the stigmatization experienced by individuals. No relationship was observed between the self-esteem

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of transplant patients and their experiences of stigmatization.

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