

# COMPREHENSIVE ASSESSMENT OF THE QUALITY OF LIFE IN HEART TRANSPLANT RECIPIENTS: EXPERIENCE AT SHUMAKOV NATIONAL MEDICAL RESEARCH CENTER OF TRANSPLANTOLOGY AND ARTIFICIAL ORGANS

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Heart transplant (HT) is an effective treatment option for patients with end-stage chronic heart failure, as it can restore their ability to work, facilitate physical and social rehabilitation, and significantly improve their long-term survival. **Objective:** to evaluate the psychological and physical well-being of HT recipients using a comparative analysis of the TxEQ, PTGI, and SF-36 questionnaires and the impact of the obtained results on the frequency of visits to health care facilities. **Materials and methods.** The findings of the study were derived by analyzing the data of recipients by random randomization, who were observed on an outpatient basis at Shumakov National Medical Research Center of Transplantology and Artificial Organs. The TxEQ, SF-36, and PTGI questionnaires were used to assess recipients' psychological and physical well-being. For comparative analysis, HT recipients were divided into three equal groups based on the total score obtained when assessing each factor in the TxEQ questionnaire. Results. A comparative evaluation of factors from the TxEQ questionnaire and scores from the SF-36 questionnaire revealed that recipients who scored poorly on a particular factor had better mental health ( $p = 0.02$ ). Recipients who are more eager to inform others about their surgery show better vitality ( $p = 0.019$ ). Analysis of the "Medication adherence" factor found that there was a significantly high compliance of recipients to taking their medications ( $p = 0.01$ ). Subsequent data analysis showed that the total PTGI score strongly correlated with the factors "Responsibility", "New life perspectives", "Disclosure" and "Medication adherence" ( $p < 0.005$ ). While analyzing factors from the TxEQ questionnaire and the frequency of recipients' outpatient visits to health care facilities, it was revealed that recipients who were more worried about their surgery and those who exhibited high medication adherence during the follow-up year visited health care facilities more often ( $p < 0.005$ ). **Conclusion.** Regularly assessing the quality of life in HT recipients is a key factor of outpatient follow-up, which allows to significantly improve physical and psychological well-being, and ultimately preventing the risk of negative health complications.

*Keywords: heart transplantation, quality of life, SF-36 questionnaire, PTGI questionnaire, TxEQ questionnaire, outpatient follow-up.*

## INTRODUCTION

For patients with end-stage chronic heart failure, a heart transplant (HT) is widely considered the primary and often only option for a radical treatment, significantly improving their life expectancy [1]. However, not only the life expectancy of HT recipients is important, but also their quality of life, which depends on various factors often not directly related to the general state of health [2]. These include socio-demographic characteristics, daily activity levels, comorbid conditions, frequency of hospitalizations, medication side effects, and personal traits [3]. Given these complexities, regular clinical

and diagnostic assessments must be complemented by psychosocial evaluations, as disruptions in psychosocial well-being can lead to poor treatment adherence, increased morbidity and mortality, and difficulties in post-transplant adaptation [4]. As a result, the number of studies assessing the physical and psychological health of HT recipients and analyzing their quality of life is steadily increasing. However, there is no single internationally recognized methodology for evaluating post-transplant quality of life. Instead, a variety of standardized questionnaires are used, including the Transplant Effects Questionnaire (TxEQ), Post-Traumatic Growth Inventory (PTGI), and the Short Form Health Survey (SF-36).

These tools assess both physical and psycho-emotional well-being, as well as patients' satisfaction with their functional status. Their use enables early identification of potential risks in long-term follow-up, allowing for timely interventions to enhance the quality of life for HT recipients.

**The objective of our study** was to assess the psychological and physical well-being of HT recipients through a comparative analysis of the TxEQ, PTGI, and SF-36 questionnaires and to evaluate how these results influence the frequency of healthcare visits.

## MATERIALS AND METHODS

Study participants were randomly selected from HT recipients receiving outpatient care at the Shumakov National Medical Research Center of Transplantology and Artificial Organs ("Shumakov Center"). Their health status was monitored by cardiologists and psychologists at the Shumakov Center's consulting and diagnostic department, as well as by specialists at their place of residence. Remote consultations were also conducted via telemedicine.

All recipients received a standard immunosuppressive regimen consisting of tacrolimus, mycophenolate mofetil, and methylprednisolone. Routine postoperative assessments included clinical evaluations, laboratory tests (general and biochemical bloodwork, immunosuppressive drug levels), echocardiography, and annual coronary angiography with endomyocardial biopsy.

Additionally, we collected data on recipients' social status (living conditions, marital status, and education), as well as medical records and outpatient charts from the Shumakov Center. All patients were treated in accordance with established clinical guidelines.

The TxEQ (Transplant Effects Questionnaire) [5] was used to assess the psychological status of HT recipients. This questionnaire was translated and adapted for HT recipients in collaboration with a psychologist from the Shumakov Center. It consists of 26 items divided into 5 sections; each item is scored from 1 (completely disagree) to 5 (completely agree). The sections are outlined in Table 1.

The TxEQ evaluates key psychological aspects experienced by HT recipients, including concerns about

Table 1

### Transplant Effects Questionnaire

	Points
<b>Factor 1: Worry about the transplant</b>	
I am worried about how reliable my new heart is	1–5
I feel like my heart is "fragile"	1–5
I hesitate to do certain activities for fear of harming my new heart	1–5
I wonder how long my new heart will last	1–5
I have started to take better care of myself since the transplant	1–5
I worry every time my doctor adjusts my medications	1–5
I find it hard to trust doctors	1–5
<b>Factor 2: Disclosure</b>	
I avoid telling other people that I have a transplant	1–5
I feel uncomfortable when other people know that I have had a heart transplant	1–5
I find it hard to talk about the fact that I had a transplant	1–5
I am not ready to tell everyone that life after a transplant is just beginning	1–5
<b>Factor 3: Medication adherence</b>	
Sometimes I deliberately do not take my medication	1–5
Sometimes I forget to take my medication	1–5
I might get distracted and forget to take my medication	1–5
Sometimes I think I can do without medication	1–5
I find it inconvenient for me to take my medication at the same time	1–5
I don't always follow my doctor's instructions	1–5
<b>Factor 4: Responsibility</b>	
I feel a sense of duty to the doctors who performed my successful surgery	1–5
I feel a sense of duty to my family and other people close to me	1–5
I am sometimes haunted by guilt	1–5
I usually try not to do things that could cause condemnation from my family and other close people.	1–5
<b>Factor 4: New life perspectives after transplant</b>	
I have a sense of purpose in my life after the heart transplant	1–5
I have become more interested in playing sports after the transplant	1–5
I feel that my quality of life has improved after the transplant	1–5
I feel energized after the transplant to pursue my dreams	1–5
I have returned to my normal routine after the transplant	1–5

the transplant, willingness to disclose their transplant status (renamed “Disclosure” for clarity), adherence to medication, and feelings of obligation toward family, friends, and medical staff. Higher scores indicate a stronger presence of the corresponding factor, except for “Medication adherence” and “Disclosure”, which exhibit a negative correlation.

All patients provided informed voluntary consent before undergoing psychological assessment. For comparative analysis, recipients were divided into three equal groups based on their total scores for each TxEQ factor.

The PTGI questionnaire [6] was used to assess positive psychological and emotional changes in individuals following psychological trauma or stressful experiences. It comprises 21 items divided into five domains: Relating to Others (7 items), New Possibilities (5 items), Personal Strength (4 items), Existential and Spiritual Change (2 items), and Appreciation of Life (3 items). Each item is rated on a 6-point Likert scale, reflecting the extent to which the respondent has experienced these changes due to the trauma.

The SF-36 questionnaire was used to evaluate both the physical and psychoemotional components of quality of life. The results provide insights into overall well-being and the level of satisfaction in health-dependent aspects of daily life [7]. This questionnaire consists of 36 questions covering the following eight key health domains:

1. *Physical functioning*. Measures limitations in daily physical activities like self-care, walking, climbing stairs, carrying heavy objects, etc. Lower score signifies greater limitations in daily physical activities due to the disease.
2. *Role limitations due to physical health problems*. Measures how much a person’s physical health issues interfere with their ability to perform their usual roles and responsibilities in daily life, such as work, household chores, or other activities.
3. *Role limitations due to emotional problems*. Measures how much a person’s daily activities and responsibilities are restricted or impacted by their emotional state (including more time, less work, lower quality, etc.). A lower score signifies greater impact of emotional problems on daily activities, indicating significant impairment in work and role functioning.
4. *Social functioning*. Measures how physical and emotional health problems affect a person’s ability to engage in social activities (communication). Lower score indicate restrictions in social interactions due to physical or emotional health issues, potentially indicating reduced level of communication.
5. *Bodily pain*. Measures the intensity of pain and its impact on daily activities, including housework. Lower score signifies severe pain that significantly affects daily function and work capacity.

6. *Vitality (energy or fatigue)*. Measures overall energy level and fatigue, essentially gauging how “worn out” or “vigorous” they feel. Lower score suggests experiencing more fatigue and exhaustion.

7. *Mental health*. Lower score suggests emotional distress, anxiety, or depressive symptoms.

8. *General health perceptions*. Measures an individual’s current state of health and overall view of their health status. Lower score suggests poor health perceptions.

The SF-36 questionnaire generates scores ranging from 0 to 100, where a higher score indicates a better perceived quality of life across the various health domains.

The data are presented as the arithmetic mean and standard deviation ( $M \pm SD$ ). Pearson’s chi-square test was used to assess the statistical significance of relationships between two categorical variables. For comparative analysis, the one-way nonparametric Kruskal–Wallis test was employed to evaluate variance. When significant differences were identified, pairwise multiple comparisons were conducted using the least significant difference (LSD) criterion test. Statistical analyses were performed using IBM SPSS Statistics, with hypotheses tested at a significance level of  $p < 0.005$ .

Cronbach’s alpha coefficient was calculated to measure the reliability of the TxEQ questionnaire.

## RESULTS

A representative sample was drawn from patients under outpatient follow-up at the Shumakov Center between 2009 and 2022. A randomized selection process identified a cohort of 607 recipients with a mean age of  $46.74 \pm 10.72$  years, including 509 men (83.8%). The study excluded cases of heart retransplantation, in-hospital mortality, and recipients younger than 18 years. The mean follow-up period was  $9.4 \pm 3.5$  years.

Cronbach’s alpha coefficient was calculated for each section of the TxEQ questionnaire, with the results presented in Table 2.

Analysis of the results indicated that the Cronbach’s alpha coefficient for each section of the TxEQ questionnaire was satisfactory, confirming the questionnaire’s reliability as an assessment tool.

Comparisons of TxEQ factors based on gender, marital status, and education level revealed statistically signi-

Table 2

**Calculation of Cronbach’s alpha for each section of the TxEQ questionnaire**

Factor	Cronbach’s alpha
Worried about the heart transplant performed	0.766
Disclosure	0.759
Adherence to immunosuppression	0.758
Responsibility	0.759
New life perspectives after transplant	0.794

ficant trends. Married recipients exhibited greater anxiety about their HT surgery, demonstrated higher adherence to drug therapy, showed a stronger motivation to inform others about their transplant, and felt a greater sense of duty toward their family, friends, and physicians for the success of their surgery.

Men reported greater concern about their surgical treatment and displayed greater responsibility in adhering to drug therapy ( $p < 0.005$ ). Furthermore, recipients who scored high on the factor “Worried about the heart transplant performed” tended to have a higher level of education than those with lower scores ( $p < 0.005$ ).

### COMPARATIVE EVALUATION OF THE TXEQ QUESTIONNAIRE FACTORS AND SF-36 INDICATORS

Analysis using the TxEQ indicated that transplant recipients who score lower on the “Worry about the transplant” subscale tend to demonstrate a higher level of mental health ( $p = 0.02$ ). The results suggest that recipients who exhibit less anxiety about their HT surgery are also less prone to depressive and anxiety-related states.

Subsequently, the SF-36 questionnaire results were analyzed in relation to the “Disclosure” factor to assess its impact on quality of life. It was revealed that recipients who are more motivated to share their surgery experience have higher Vitality scores, as shown in Fig. 1. The findings demonstrate that recipients who are able to talk openly about their heart transplant surgery and related experiences show better vitality ( $p = 0.019$ ).

Analyzing the data obtained for the factor “Medication adherence”, a reliably high compliance of recipients to taking prescribed medications was revealed. Fig. 2, indicates a statistically significant negative relationship between high medication adherence scores and lower mental health scores ( $p = 0.01$ ).

Individuals with higher “Mental health” scores tend to have lower adherence to therapy. The obtained result indicates the presence of depressive, anxious feelings, and mental distress, which reflects the instability of psycho-emotional state due to irregular intake of medications and possible complications arising from the lack of adequate drug treatment.

When evaluating the factor “Responsibility” from the TxEQ questionnaire, a negative correlation was established: as “Responsibility” scores increased, scores for “Physical Functioning” ( $p = 0.008$ ), “Role limitations due to emotional problems” ( $p = 0.047$ ) and “General health perceptions” ( $p = 0.05$ ) from the SF-36 questionnaire decreased. Based on these findings, it can be concluded that recipients who experience an increased sense of responsibility for the success of their HT surgery may face limitations in daily life due to a decline in physical health, exacerbated by emotional distress and psycho-emotional destabilization.

In further assessment of the factor “New life perspectives after transplant”, individuals who score higher on measures of “New life perspectives after transplant” tend to exhibit higher “Physical functioning” scores compared to those with lower ( $p = 0.004$ ) or average ( $p = 0.007$ ) scores. This indicates the importance of forming a posi-

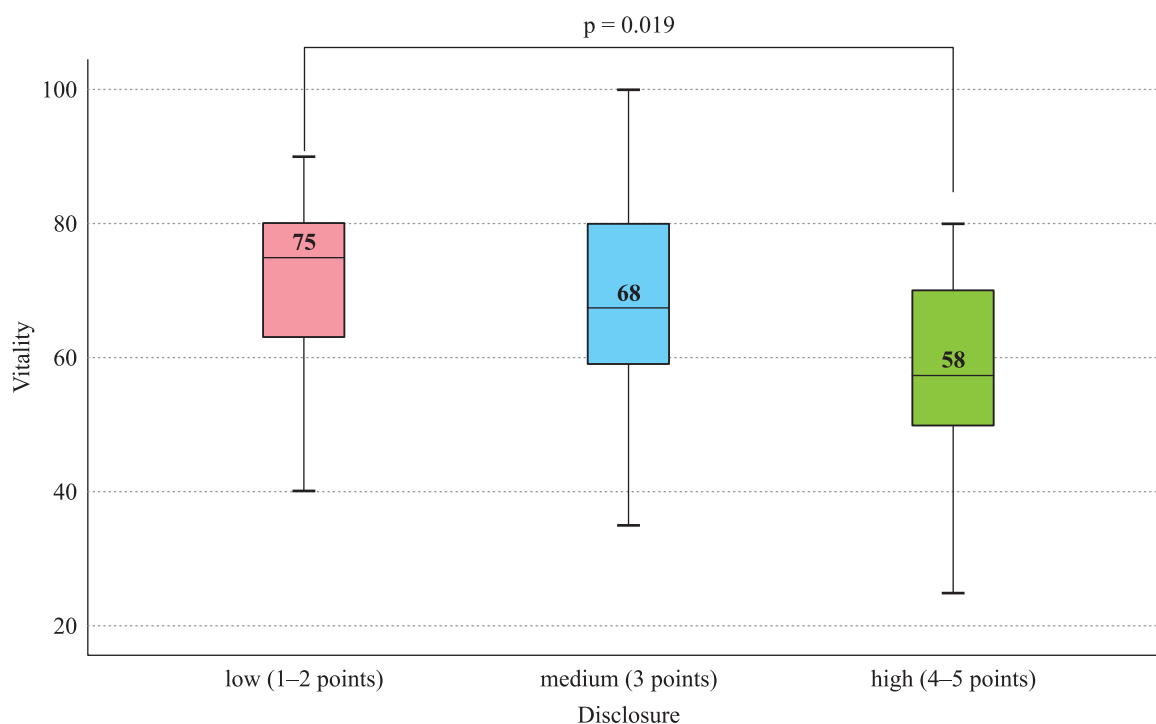


Fig. 1. Comparative analysis of the factor “Disclosure” (TxEQ questionnaire) and the indicator “Vitality” (SF-36 questionnaire)

tive image of the future and vision of new perspectives within the framework of improving the general physical condition (Fig. 3).

Further analysis assessed the impact of the total PTGI score on TxEQ factors, revealing a significant positive correlation between the PTGI total score and the fac-

tors “Responsibility” and “New life perspectives after transplant”. These findings suggest that transplant recipients undergo profound life changes, often marked by an existential crisis, personalization of life and death issues, internal conflict, and a search for new meaning and redefinition of existence ( $p < 0.005$ ).

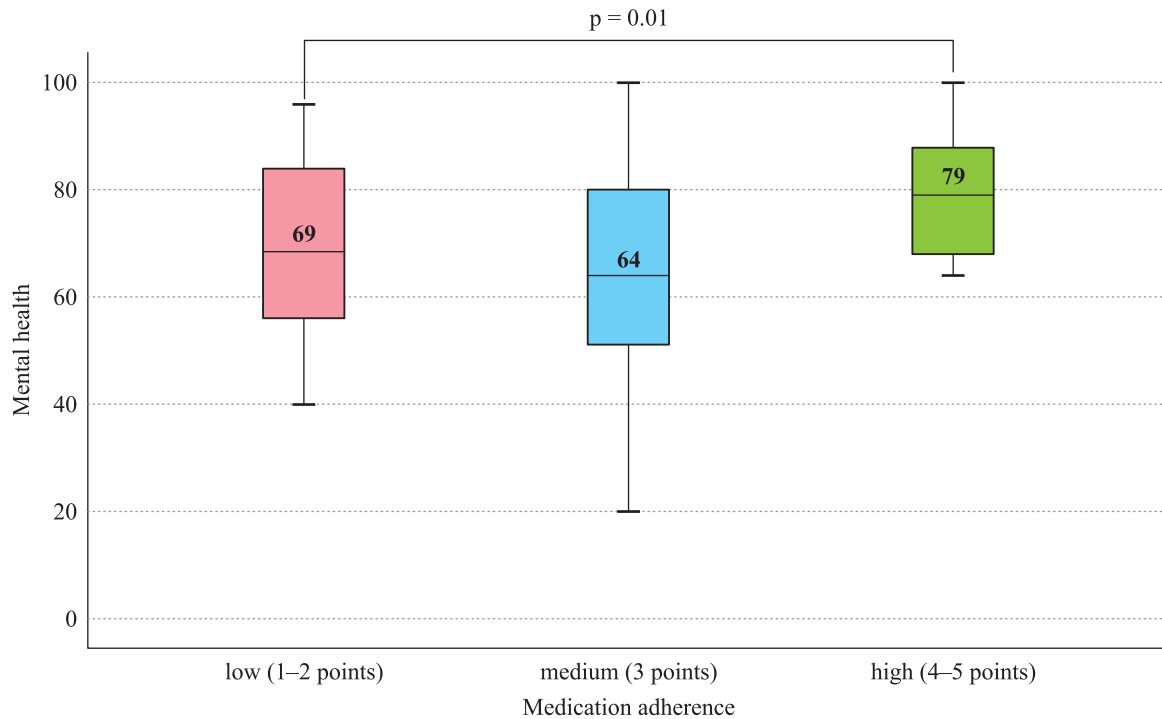


Fig. 2. Comparative analysis of the factor “Medication adherence” (TxEQ questionnaire) and the indicator “Mental health” (SF-36 questionnaire)

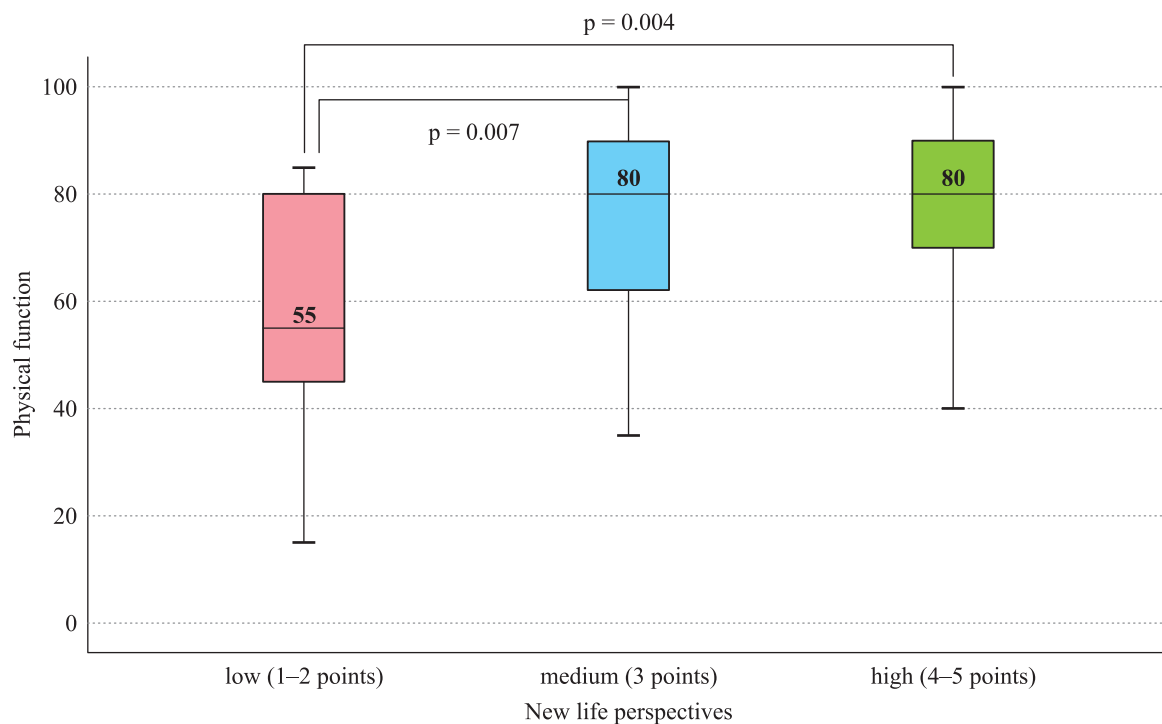


Fig. 3. Comparative analysis of the factor “New life perspectives” from the TxEQ questionnaire and the indicator “Physical function” from the SF-36 questionnaire



A comparison of “Medication adherence” with the total PTGI score indicated a statistically significant inverse correlation, where recipients with higher adherence to drug therapy tended to have lower PTGI scores, while those with higher PTGI scores exhibited lower adherence ( $p = 0.017$ ). Additionally, recipients who openly shared their transplant experience demonstrated significantly higher PTGI scores, highlighting the role of disclosure in psychological growth after HT.

The analysis revealed a correlation between TxEQ factors and the frequency of recipients’ outpatient visits to medical facilities. Recipients who exhibited greater anxiety about their HT surgery and demonstrated high adherence to drug therapy during the first year of follow-up were more likely to visit clinical and diagnostic departments, both at the Shumakov Center and other healthcare institutions.

Notably, the high frequency of outpatient visits was not associated with adverse events but rather with increased patient vigilance regarding their health condition ( $p < 0.005$ ).

## DISCUSSION

This study is the first in Russian literature to provide a detailed assessment of quality-of-life indicators in a large cohort of HT recipients, utilizing a comparative analysis of three standardized questionnaires – key tools for evaluating treatment outcomes [7].

Our comparative evaluation of sex, marital status, and TxEQ factors revealed that married men demonstrated greater adherence to drug therapy. These findings align with results from a study conducted by Jia-Rong Wu et al. [8]. However, similar patterns were not confirmed in the findings of other researchers [9, 10].

Our study provided compelling evidence that recipients who exhibited greater concern about their HT surgery demonstrated better mental health. This finding is likely explained by the fact that these recipients more frequently sought medical consultations, leading to greater awareness of their health status, which may positively influence their mental well-being.

Similarly, Richard Klaghofer et al. [5] highlight the importance of specialist consultations in assessing not only the physical but also the mental health of recipients. However, their study found that better mental health was observed in patients who were less concerned about their surgery.

Thus, early detection of psychological issues in transplant recipients plays a crucial role in maintaining emotional stability and reducing the risk of complications [11].

A study conducted in Poland reported that recipients who were more motivated to inform others about their HT surgery demonstrated higher vitality scores [10]. These scores are linked to positive lifestyle changes and improved quality of life post-transplant, findings that are also supported by the results of our study.

Further assessment of psycho-emotional status revealed that recipients with lower medication adherence exhibited greater emotional instability and were more prone to depressive and anxious experiences. Similarly, Brocks et al. [12] found that recipients who adhered to their medication regimen had higher mental health scores. Our study yielded comparable results, demonstrating a significant association between the “Medication adherence” factor from the TxEQ questionnaire and the “Mental health” indicator from the SF-36 questionnaire.

Our study also provided strong evidence that recipients who felt an increased sense of responsibility for the success of their HT surgery – toward their family, relatives, and physicians – experienced a decline in physical health and psycho-emotional destabilization. However, a study by Natalie Engelbrecht found that personal responsibility was not a predictor of quality of life [13].

When assessing the “New life perspectives after transplant” factor from the TxEQ questionnaire, our findings demonstrated that HT recipients experienced improved quality of life and social adaptation, driven by a positive perception of future prospects and life goals post-transplant. These results are consistent with findings from international studies [14, 15].

Further evaluation of the influence of total PTGI score on TxEQ factors revealed that recipients with the highest PTGI scores were those who were highly motivated to inform others about their surgery, exhibited strong adherence to drug therapy, and demonstrated a high level of personal responsibility. These findings align with results from previous studies confirming the impact of the PTGI score on TxEQ factors [9, 5, 16, 17].

Moreover, successful post-transplant recovery has been shown to be directly linked to several key factors: personal responsibility, adherence to prescribed therapy, and a positive outlook. These elements play a crucial role in facilitating significant cognitive and emotional transformations following a major traumatic event such as transplant surgery [18, 19].

A study by Samar Tharwat et al. found that patients with high medication adherence had more frequent outpatient visits compared to those with lower adherence to therapy [20]. Our study similarly confirms that recipients with higher adherence to prescribed treatments tend to visit healthcare facilities more frequently for follow-ups and monitoring.

## CONCLUSION

Following HT, recipients experience significant improvements in both psychological and physical quality of life, largely due to a personalized approach to outpatient follow-up. Regular check-ups, continuous health monitoring, and enhanced adherence to treatment play a crucial role in improving mental and physical health indicators while also reducing the risk of adverse events.

Therefore, to maintain a high quality of life among HT recipients, it is essential to provide consistent medical supervision, conduct regular psycho-emotional assessments, implement strategies to enhance social adaptation.

*The authors declare no conflict of interest.*

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