Quality of Life of Patients that Had a Heart Transplant: Application of Whoqol-Bref Scale

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Abstract
Background: The success of cardiac transplantation involves ensuring the survival of patients with heart disease and allowing them to carry out their daily activities. Heart transplant is the first option of treatment for heart failure and it represents an increase in the survival rate and quality of life of transplant patients.

Objective: To evaluate the quality of life of patients that had a heart transplant by using a standardized scale (Whoqol-Bref).

Methods: A quantitative descriptive exploratory study, conducted with 55 patients that had a heart transplant, in a period ranging between the third and 103rd months, who were monitored at the Transplant and Heart Failure Unit in a benchmark cardiology hospital in the city of Fortaleza, State of Ceará. The data were collected from February 2009 to April 2009, by administering a WHO-standardized questionnaire and by using data contained in medical records.

Results: With respect to the physical domain, 62.8% of male patients and 58.3% of female patients are satisfied. In the psychological domain, 65.1% of males are satisfied with the quality of life and, 58.3% of females are satisfied. In terms of social relations, it was observed that 53.5% of males are very satisfied and 100% of females are satisfied. With regard to the environment, 65.1% of male patients and 83.3% of female patients are satisfied.

Conclusion: The heart transplant had a lot of influence on the quality of life of transplant patients, because the results have proven to be statistically significant after the transplant. (Arq Bras Cardiol 2011; 96(1): 60-67)

Keywords: Heart transplantation; quality of life; questionnaires; psychological tests.

Introduction
The success of cardiac transplantation involves ensuring the survival of patients with heart disease and allowing them to carry out their daily activities with quality. Heart transplant is the first option of treatment for heart failure and it represents a significant increase in the survival rate and quality of life of transplant patients¹.

According to ABTO (Brazilian Association of Organ Transplantation), until September 2009, a total of 147 heart transplants from deceased donors had been performed in Brazil. From January 1999 to September 2009, in Brazil, a total of 1,722 heart transplants were recorded².

Cardiomyopathy, ischemic heart disease, valvular disease, rejection of previously transplanted hearts and congenital heart disease are the main disorders for which heart transplant is indicated³.

There is a concern for the quality of life of human beings, especially for heart transplant recipients, as they require rigorous care and greater support from the family and from the health team.

Quality of life is self-esteem and personal well-being and it includes a number of aspects, such as functional capacity, socioeconomic status, emotional state, social interaction, intellectual activity, self care, family support, one’s own health, cultural values, ethical values and religion, lifestyle, satisfaction with one’s job and with daily activities and the environment in which one lives⁴.

Patients who are on waiting lists for cardiac transplantation have to cope with feelings of abandonment, depression, hopelessness, anxiety and decreased self-esteem, among others. As a result, such patients and their families end up developing reactions to the disease. Furthermore, the history of the disease, the aspects that triggered such disease, the interaction, assessment and response of the individual in relation to threats to his or her well-being may moderate the impact and stop or accelerate the development of a disease process⁵.

It is well known that patients with heart disease need to change their lifestyle, and this affects the quality of life,
especially of individuals that had a transplant.

In this study, the purpose was to evaluate the quality of life of patients that had had a heart transplant by using a standardized scale (WHOQOL-Bref).

**Method**

This study is classified as exploratory and descriptive and it is based on a quantitative approach. The exploratory research aims to provide comprehension of the problem of the study, making it more explicit by considering various aspects of the phenomenon under study.

Quantitative research is the most appropriate method of social investigation to study explicit and conscious attitudes and opinions of respondents, through the use of standardized instruments, which use statistical techniques for interpreting data. This research acknowledges the value of numerical data that allow making projections for the population represented and, it is a method used when there are usable and valid measuring instruments, so as to ensure the objectivity and credibility of data.

The research was conducted at the outpatient clinic of the Heart Failure and Transplantation Unit (UTIC), of a benchmark cardiology hospital in the city of Fortaleza, Ceará State (Brazil). This is a tertiary unit that specializes in the diagnosis and treatment of heart and lung diseases, offering all the high-complexity procedures in such areas. The institution serves patients from the 184 municipalities in Ceará State and from the North and Northeast, and it is a national center of excellence in heart transplantation in adults and children.

The study population consisted of adult patients that had heart transplant and who were being monitored at the outpatient clinic (UTIC) of a benchmark hospital in the city of Fortaleza, Ceará State. The following inclusion criteria were adopted: to be more than 18 years-old, to be in the postoperative period of heart transplantation, to have had the surgery three months or more before the research, to be being monitored at the institution’s outpatient clinic and to agree to take part in the research.

We excluded patients under 18 years of age, patients that were in the period immediately after the surgery, patients being monitored at outpatient clinics outside the state, people with mental disabilities, those who refused to participate in the study and the ones that died during the collection period.

The study included a total of 55 patients from 19 to 71 years of age, who had had cardiac transplantation in the corresponding period between the third and 103rd months and who were being monitored at the outpatient clinic (UTIC), in accordance with the inclusion criteria. Only three patients refused to take part in the research.

The data were collected between February and April 2009, at the outpatient clinic of the benchmark heart transplant hospital in the city of Fortaleza, state of Ceará. The data were collected by administering a standardized structured quality-of-life questionnaire (WHOQOL-Bref), which is a generic instrument developed by the World Health Organization, in an abbreviated version of the WHOQOL-100, which measures the individuals’ perception of the impact that the diseases make on their lives. Medical records were also used as a source of data, in search of identification information, transplantation date and pathology of indication for transplantation.

The WHOQOL-Bref consists of 26 closed questions that had the best psychometric performance in the WHOQOL-100, including two general questions about quality of life and other 24 questions representing each one of the 24 facets that comprise the original instrument. These 24 questions are grouped into 4 domains: physical (7 items), psychological (6 items), social (3 items) and environment (8 items).

The application of this scale is intended to measure quality-of-life aspects of patients who underwent heart transplantation, considering the impact suffered and the effects of the surgical treatment in various dimensions.

The WHOQOL project develops a scale from a cross-cultural perspective, to measure the quality of life of adults, with fundamental characteristics of quality-of-life subjectivity, focusing on positive and negative aspects, and multidimensional character.

The data collected were stored in SPSS 14.0 and organized in tables. After that, a descriptive statistical analysis of such data was conducted. We used the LRT (Likelihood Ratio Test) association test and correlation coefficient (Pearson r) for the association analyses. The results were discussed by comparing such results to the relevant literature.

The research was based on the principle that it was important to comply with Resolution 196/96 of the National Health Council, which addresses the ethical aspects of research involving humans. This project was submitted to the Research Ethics Committee (REC) of the Hospital where the study was conducted, and it was approved under protocol number 582/08 for beginning of the research in the field.

The patients signed a Consent Form authorizing the inclusion of such patients in the research.

**Results**

After organizing and analyzing the data, we initially presented the socio-demographic information, including variables such as age, sex, time since transplant and base pathology, as outlined below.

Most study participants were men, who accounted for 43 patients (78.2%). Ages ranged from 19 to 71 years-old. The 49 to 59 age group prevailed in the study, with 26 (47.3%) heart transplant patients. The second age group was the one from 19 to 48 years of age, with 17 (30.9%) patients, and the least frequent age group was the one between 60 and 71 years of age, with 12 (21.8%) patients.

Fifteen patients (27.3%) had had the transplant between 3 and 12 months before the research (most common “time since transplant”), and 13 patients (23.6%) had undergone the surgery between 61 and 103 months before the research (second most common time). Twelve (12) patients (21.3%) had the surgery between 13 and 24 months before the research, and 9 (16.4%) had it between 37 and 60 months before the research. Six (10.9% [the smallest percentage in the study]) patients that went to the outpatient clinic during the research had had the transplant between 25 and 36 months before the research.
With respect to the transplant patients’ pathology type, it was found that most patients (18 of the transplant patients [32.7%]) had ischemic cardiomyopathy; 15 patients (32.7%) had idiopathic dilated cardiomyopathy; 8 patients (14.5%) had Chagas cardiomyopathy; 7 patients (12.7%) had alcoholic cardiomyopathy, and 7 patients (12.7%) also had other diseases.

With regard to the general questions assessed about the quality of life, the results represent the patients’ satisfaction with their health after transplantation, according to gender, age and time after surgery, as shown in Table 1.

Among males, there was predominance of satisfaction with the quality of life, including 22 patients (51.2%) satisfied, out of a total of 55, and it is worth highlighting that only 8 respondents were moderately satisfied (median). On the other hand, among women, the level of satisfaction was of 100%, including 6 (50%) women satisfied and 6 (50%) women very satisfied.

With respect to the age group from 19 to 48 years of age, 9 (52.9%) patients said they were satisfied with their quality of life and 8 (47.1%) said they were very satisfied. In the 49 to 59 and 60 to 71 age groups, there was a noticeable decline represented by 5 (19.2%) of all 26 patients and 3 (25%) of 12 transplant recipients, respectively, regarding the satisfaction with their quality of life.

With respect to the “time since transplant” (Tx), it was found that the patients that had had the transplant from 3 to 12 months before the research and from 13 to 24 months before the research included 7 (46.7%) and 8 (66.7%) patients, respectively, who were satisfied, and eight (53.3%) and 4 (33.3%) patients, respectively, who were very satisfied. In the Tx of 25 to 36 months, three (50%) said they were satisfied, and two (33.3%) said they were moderately satisfied (median level). In the 49 to 59 age group, 14 (53.8%) patients said they were satisfied and 10 (38.5%) said they were somewhat satisfied, in a population of 26 transplant recipients. In the age group from 60 to 71 years of age, 8 (66.7%) said they were satisfied and only 4 (33.3%) were at a median level of satisfaction with respect to their physical domain.

With respect to the “time since transplant” (Tx), it was found that the patients that had had the transplant from 3 to 12 months before the research and from 13 to 24 months before the research included 7 (46.7%) and 8 (66.7%) patients, respectively, who were satisfied, and 8 (53.3%) and 4 (33.3%) patients, respectively, who were very satisfied. In the Tx of 25 to 36 months, three (50%) said they were satisfied, and two (33.3%) said they were moderately satisfied (median level). In the Tx of 37 to 60 months, 4 (44.4%) were satisfied, two (22.2%) were very satisfied and three (33.3%) were moderately satisfied (median level). Among patients that had had the transplant from 61 to 103 months before the research, six (46.2%) said they were satisfied, 4 (30.8%) were very satisfied and three (23.1%) were at a median level of satisfaction.

The psychological domain is characterized by questions that portray the meaning of life, way of enjoying life, concentration,
Table 2 - Distribution of patients according to the physical domain. City of Fortaleza, State of Ceará, 2009

<table>
<thead>
<tr>
<th></th>
<th>V3*</th>
<th>V4†</th>
<th>V5‡</th>
<th>LRT§</th>
<th>p//</th>
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<td>n</td>
<td>%</td>
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<tr>
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<td>7</td>
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<td>8</td>
<td>66.7</td>
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<td>3</td>
<td>50</td>
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<td>4</td>
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<tr>
<td>61 to 103</td>
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<td>23.1</td>
<td>6</td>
<td>46.2</td>
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</tbody>
</table>

*V3 - Intermediate satisfaction/moderately satisfied (median); †V4 - Satisfied; ‡V5 - Very satisfied; §LRT - Likelihood ratio test; //p - Pearson Coefficient.

acceptance of physical appearance, satisfaction with oneself and frequency of negative feelings.

According to Table 3 of the psychological domain, among the male patients, in a population of 43 respondents, 28 (65.1%) were satisfied with the quality of life and 15 (34.9%) were moderately satisfied (median level). Among the women, 7 (58.3%) were satisfied and five (41.7%) were at a median level of satisfaction.

With respect to the age group from 19 to 48 years of age, 12 (70.6%) said they were satisfied and only 5 (29.4%) had median quality of life. In the age group from 49 to 59 years of age, it was found that 14 (53.8%) patients were satisfied and 10 (38.5%) were at a median level of satisfaction, out of a total of 26 transplant recipients. In the 60 to 71 years age group, it was possible to note that 8 (66.7%) were satisfied and only 4 (33.3%) were moderately satisfied (median level).

With respect to the “time since transplant” (Tx), among those interviewed in the period between 3 and 12 months after the transplant, 12 (80%) were satisfied with their quality of life, out of a total of 15 transplant patients. In the Tx of 13 to 24 months, 8 (66.7%) were satisfied and 4 (33.3%) were moderately satisfied (median level). In the 25-36 month period, 4 (66.7%) patients were satisfied and two (33.3%) were at a median level of satisfaction. As to the period of 37-60 months, there was a decline in quality of life of transplant patients, because 6 (66.7%) answered that their life was at a median level, and only three (33.3%) were satisfied. In the Tx between 61 and 103 months, 8 (61.5%) said they were

Table 3 - Distribution of patients according to the psychological domain. City of Fortaleza, State of Ceará, 2009

<table>
<thead>
<tr>
<th></th>
<th>V3*</th>
<th>V4†</th>
<th>V5‡</th>
<th>LRT§</th>
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</tr>
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<td>41.7</td>
<td>7</td>
<td>58.3</td>
<td>-</td>
</tr>
<tr>
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<td>0.759</td>
</tr>
<tr>
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<td>-</td>
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<tr>
<td>49 to 59</td>
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<td>38.5</td>
<td>14</td>
<td>53.8</td>
<td>2</td>
</tr>
<tr>
<td>60 to 71</td>
<td>4</td>
<td>33.3</td>
<td>8</td>
<td>66.7</td>
<td>-</td>
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<tr>
<td>Tx Time</td>
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<td>0.249</td>
</tr>
<tr>
<td>3 to 12</td>
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<td>20</td>
<td>12</td>
<td>80</td>
<td>-</td>
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<tr>
<td>13 to 24</td>
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<td>25 to 36</td>
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<tr>
<td>37 to 60</td>
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<tr>
<td>61 to 103</td>
<td>5</td>
<td>38.5</td>
<td>8</td>
<td>61.5</td>
<td>-</td>
</tr>
</tbody>
</table>

*V3 - Intermediate satisfaction/moderately satisfied (median); †V4 - Satisfied; ‡V5 - Very satisfied; §LRT - Likelihood ratio test; //p - Pearson Coefficient.
satisfied and 5 (38.5%) reported being moderately satisfied (median level) with their quality of life.

The domain of social relationships portrays the personal relationships with friends, family and sex life. The responses were organized in Table 4.

It was observed that, among the males, 23 (53.5%) were very satisfied, 17 (39.5%) were satisfied and only three (7.0%) were moderately (median level) satisfied with their interpersonal relationships and sex life. On the other hand, among women, the level of satisfaction was of 100%, including 7 (58.3%) women that were very satisfied and 5 (41.7%) who were satisfied.

As for the 19 to 48 years age group, there was predominance of satisfaction, with 12 (70.6%) patients very satisfied and 5 (29.4%) satisfied. In the 49 to 59 and 60 to 71 age groups, 15 (57.7%) and three (25.0%) were very satisfied, respectively, and 10 (38.5%) and 7 (58.3%) were satisfied. It was possible to observe that there was almost unanimous predominance of satisfaction with interpersonal relationships and sexual activity.

With respect to the “time since transplant” (Tx), in the periods of 3 to 12 months and 25 to 36 months, there were 10 and 4 (66.7%) patients who were very satisfied, respectively, while 5 and 2 (33.3%) reported being satisfied. In the Tx corresponding to 13-24 months, 10 (83.3%) were very satisfied and two (16.7%) were satisfied. As to the periods between 37 to 60 months and 61 to 103 months, 2 (22.2%) and 4 (30.8%), respectively, were very satisfied, 5 (55.6%) and 6 (61.5%) were satisfied, and only two (22.2%) and one (7.7%) were moderately satisfied (median level) with their interpersonal relationships and sexual activity.

In this domain, out of the 43 male transplant patients, 28 (65.1%) were satisfied, 8 (18.6%) were moderately satisfied and 7 (16.3%) were very satisfied. Among the females, 10 (83.3%) were satisfied, one (8.3%) was very satisfied and one (8.3%) was at a median level of satisfaction.

As for the age group from 19 to 48 years of age, 14 (82.4%) were satisfied and only two (11.8%) patients were moderately satisfied (median level) with respect to their environment domain. And in the 49 to 59 age group, 18 (69.2%) were satisfied, 5 (19.2%) were very satisfied and three (11.5%) were moderately satisfied (i.e., at a median level). In the age group from 60 to 71 years of age, 6 (50.0%) said that they were satisfied, 4 (33.3%) were at a median level of satisfaction and two (16.7%) were very satisfied.

Discussion

With respect to socio-demographic aspects, the results of this study were consistent with data presented in the national literature. With regard to gender, the data were equivalent to ABTO’s data, considering that 75% of the patients that had the heart transplant are male. With respect to age, about 70% of patients were in the 19 to 48 years old group. In terms of time since transplant, most patients were in the 3 to 12 month period (66.7%) followed by the 13 to 24 months group (83.3%). The environment domain portrays the safety, healthy physical environment, income, availability of information, leisure, housing conditions, access to health services and means of transport, as shown in Table 5.
the patients that had a heart transplant in Brazil are between 41 and 60 years of age\textsuperscript{11}.

The highest frequency of patients in the outpatient clinic in the period from 3 to 12 months after the transplant is justified by the need to monitor the dosage of medication, to adjust the diet, psychological care, risk of rejection and infection control.

It was noticed that, over the years, transplant patients experience difficulties due to the high rate of hospitalization for suspected rejection and infection. In addition, transplant patients face late complications, such as hypertension, dyslipidemia, diabetes mellitus, among others\textsuperscript{12}. Rejections, infections and the obstruction of coronary arteries, which causes heart attack\textsuperscript{13}, are the main causes of death among these patients.

There is a high rate of coronary artery diseases in public health care, but there is a deficit in the early diagnosis of the disease, and this allows the disease to evolve to a level in which tertiary care becomes necessary. In Brazil, the main causes that lead to the transplant are: idiopathic in 39%, ischemic in 24%, and Chagas’ disease in 23%\textsuperscript{11}, which is similar to the data obtained in this research.

Heart transplant involves complex changes, restricting the recipient’s life, with alterations to family dynamics, reversal of roles, changes in social and economic life, leading to changes in the normal lifestyle of transplant patients, due to the inability to perform daily activities.

With regard to general questions about quality of life, the females’ level of satisfaction was higher when compared to males. As the women’s behavior in relation to health is more active, they seek medical care more often, and this fact results in the identification of diseases in their early stages.

The study reports that men do not give due attention to their health and, consequently, they do not seek medical care very often\textsuperscript{14}. Men, in general, do not talk about their health problems, because that would mean a demonstration of weakness before others, also meaning a kind of feminization of the notion of health care. These cultural patterns have strengthened men’s difficulty to seek health services and implement health promotion measures\textsuperscript{15}.

With respect to the time since transplant, patients that had had the transplant one year or less before the research were more satisfied with their quality of life, because they had undergone great suffering in the pre-transplant period, due to the anguish of waiting lists, hospitalization time, decreased contact with family and friends and the risk of death. In the post-transplant period, they are living a new life, with a greater degree of satisfaction with their quality of life. A study shows that patients feel relieved when they undergo the transplant, and this reduces negative feelings in this period, since patients put all their hope on the surgery\textsuperscript{1}.

In the physical domain, patients said mainly that they were moderately satisfied or moderately satisfied, but it seems that the impact on women in this domain was not as significant as the impact on men. Based on the socio-demographic characteristics identified in the study participants, it was observed that male patients before transplantation generally worked in different types of jobs, while most women were housewives.

Transplant patients change their daily life, and this is significantly detrimental to their emotional state, due to alterations to self-esteem, which result from alterations within the family and from the inability to work, which leads to increased dependence\textsuperscript{16}.

In the psychological domain, it was found that most transplant patients are moderately satisfied and satisfied with their quality of life, but none of them was very satisfied. This can occur because patients compare the pre-illness period to the period after the transplant, during which there is significant improvement in their health, but they realize they will never return to the life they led before the disease. In the study, it was possible to notice that there was a reasonable amount of patients that have negative feelings, such as depression,
anxiety and despair, which may be caused by the fact that they expected to lead a normal life, just like the routine they followed before the disease.

Our data are similar to results of other studies, which portray the quality of life of transplant patients, showing the variation in the patients’ emotional state in some periods of their life\(^\text{1}\). Patients often become depressed and find it difficult to overcome obstacles in their lives after the transplant\(^\text{11}\).

In the domain of social relations, there was a very high level of satisfaction, apart from a minimal amount of patients who were moderately satisfied (median level). It was found that most of them count on the support and sympathy of the family and friends, who encourage such patients and give them strength to overcome the disease, before and after the transplant, thereby stimulating them even more in this new phase of life, strengthening even more their family relationships and increasing their emotional confidence.

A study observed that when caregivers are present during appointments, they participate in the aspects related to the provision of patient data, they help patients follow important instructions referring to medications, to examination dates and to eating habits, besides helping identify signs and symptoms presented by patients, which are important aspects involved in the care\(^\text{16}\).

The data of this research are similar to the results of another study, which shows that there is positive correlation between the quality of life of transplant patients and their satisfaction with social support\(^\text{19}\).

In the environment domain, the transplant patients’ level of satisfaction with access to health services, housing conditions and relationship with the interdisciplinary team was satisfactory. It was noticed that the satisfaction with the means of transport was not so visible, because the majority reported using public transportation.

It was also possible to notice that the transplant patients interviewed strictly follow the treatment plan that they need to have good quality of life. The quality of life of transplant patients depends on their adherence to the treatment plan, which is characterized by self-care. The success of the treatment is directly dependent upon a good relationship between the health team and the patient, as well as upon the family’s support\(^\text{20}\).

Conclusions
The study addressed the quality of life of heart transplant patients by using a data collection instrument standardized by the World Health Organization, the WHOQOL-Bref, which allowed acquiring broad knowledge about the patients’ quality of life within a global sphere.

Heart transplantation is the only possibility for improving the quality of life of patients that have refractory heart diseases, who suffer with signs and symptoms of the disease, and who, even after adherence to and optimization of the clinical and pharmacological treatment, cannot lead a normal daily life, besides having a poor prognosis.

In this study, the heart transplantation had a lot of influence on the quality of life of transplant patients, because the results have proven to be statistically significant in the period after the transplant. Based on the data collected, it was observed that the patients are satisfied with their quality of life in all domains. It is worth highlighting that some patients said they were not satisfied, but this group was small and did not represent a statistically significant value.

Transplant patients feel fulfilled in relation to the transplant, with a great degree of satisfaction for being living a new life, because they experienced difficult times in the pre-transplant period, when they were waiting for a heart to survive.

The help of family and friends during this period is extremely important to provide emotional support and the encouragement needed to deal with this new phase of life, coupled with the monitoring of a multidisciplinary team. The higher the degree of staff-patient interaction is, the better the adherence to the treatment plan will be and, consequently, the better the patients’ quality of life will get.

The daily routine of a transplant patient differs from the routine of a person that has not had a transplant, due to the excessive care that needs to be taken in relation to infection prevention, healthy and appropriate eating habits, weight maintenance and administration of prescribed medication strictly on time, considering that the participation of health teams in health promotion measures is essential.

This research suggests the need for greater attention to negative feelings, which were mentioned quite often by the transplant patients, in addition to the need to conduct qualitative research on the subject.

Potential Conflict of Interest
No potential conflict of interest relevant to this article was reported.

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Study Association
This study is not associated with any post-graduation program.

References


