Original Article

Comparison of quality of life between patients on the waiting list and heart transplant recipients

Comparação da qualidade de vida entre pacientes em lista de espera e pacientes submetidos a transplante cardíaco

Comparación de la calidad de vida entre pacientes en lista de espera y pacientes sometidos a trasplante cardíaco

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Vanessa Monteiro Mantovani[a,b]
Cristine Behrend Silveira[c]
Lidia Lucas Lima[c]
Letícia Orlandin[b,d]
Eneida Rejane Rabelo-Silva[b,d,e]
Maria Antonieta Moraes[c]

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ABSTRACT

Objectives: To compare the quality of life (QOL) between wait-listed patients and heart transplant recipients.
Methods: Cross-sectional study of 56 adult patients at two institutions in Southern Brazil, 9(16%) wait-listed patients and 47(84%) transplant recipients. Data were collected from August to December 2012. QOL was assessed using the Medical Outcomes Study 36-Item Short-Form Health Survey (SF-36), with scores ranging from zero to 100.
Results: There was statistically significant difference between the two groups in the overall QOL score (p=0.010) and in four dimensions. The mean rank was 16.9 in wait-listed patients and 30.7 in transplant recipients. Wait-listed patients presented the lowest for general health (9.1) and the highest scores for role-emotional (24.8). Transplant recipients obtained the highest scores for general health (32.2) and the lowest scores for bodily pain (29.1).
Conclusions: Undergoing a transplant has a positive impact on the QOL of recipients compared to that of patients awaiting transplantation.
Keywords: Heart transplantation. Quality of life. Patient care team.

RESUMO

Objetivos: Comparar a qualidade de vida (QV) entre pacientes em lista de espera e pacientes submetidos a transplante cardíaco.
Métodos: Estudo transversal conduzido com 56 pacientes adultos em duas instituições de referência no sul do Brasil, 9(16%) em lista de espera e 47(84%) transplantados. A coleta de dados ocorreu entre agosto e dezembro de 2012. Utilizou-se o Medical Outcomes Study 36-item Short-Form Health Survey (SF-36), com escores variando de zero a 100.
Resultados: Houve diferença estatística no escore geral da QV entre os grupos (p=0,010) e em quatro domínios. A média das ordenações (mean rank) foi igual a 16,9 nos pacientes em lista de espera e 30,7 nos pacientes transplantados. Pacientes em lista de espera tiveram o menor escore no estado geral de saúde (9,1) e maior escore nos aspectos emocionais (24,8); pacientes transplantados apresentaram maior pontuação no estado geral de saúde e pior pontuação na dor (29,1).
Conclusões: A realização de transplante impacta positivamente na QV dos pacientes, quando comparada à CV daqueles em lista de espera.
Palavras-chave: Transplante de coração. Qualidade de vida. Equipe de assistência ao paciente.

RESUMEN

Objetivo: Comparar la calidad de vida (CV) entre pacientes en lista de espera y pacientes sometidos a trasplante cardíaco.
Método: Estudio transversal, realizado con 56 pacientes adultos en las dos instituciones más importantes en el sur de Brasil, 9(16%) en lista de espera y 47(84%) sometidos a trasplante de corazón. Los datos fueron recogidos entre agosto y diciembre de 2012. Se utilizó el Medical Outcomes Study 36-item Short-Form Health Survey (SF-36), con puntuaciones que van de cero a 100.
Resultados: Hubo diferencia estadísticamente significativa en la puntuación global de QV entre los grupos (p=0.010) y en cuatro dominios. El promedio de las ordenaciones (mean rank) fue igual a 16,9 en pacientes en lista de espera y 30,7 en pacientes con trasplante. Los pacientes en lista de espera tuvieron la puntuación más baja en la salud general (9.1) y la puntuación más alta en los aspectos emocionales (24.8); pacientes con trasplante mostraron puntuaciones más altas en el estado general de salud y la peor puntuación en el dolor (29.1).
Conclusión: El trasplante cardíaco provoca impacto importante en el aumento de la QV en comparación con pacientes en lista de espera.
Palabras clave: Trasplante de corazón. Calidad de vida. Grupo de atención al paciente.

[a] Pontifícia Universidade Católica do Rio Grande do Sul (PUCRS), Hospital São Lucas. Porto Alegre, Rio Grande do Sul, Brasil.

[b] Universidade Federal do Rio Grande do Sul (UFRGS), Escola de Enfermagem, Programa de Pós-graduação em Enfermagem. Porto Alegre, Rio Grande do Sul, Brasil.

[c] Instituto de Cardiologia (IC-FUC). Porto Alegre, Rio Grande do Sul, Brasil.

[d] Hospital de Clínicas de Porto Alegre (HCPA). Porto Alegre, Rio Grande do Sul, Brasil.

[e] Universidade Federal do Rio Grande do Sul (UFRGS), Escola de Enfermagem. Departamento de Enfermagem Médico-Cirúrgica. Porto Alegre, Rio Grande do Sul, Brasil.

INTRODUCTION

Heart transplantation is the best surgical treatment option for patients with heart failure (HF) refractory, although there is great improvement in life expectancy with clinical treatment. HF is considered refractory in patients with severe symptoms and marked limitation of activities of daily living and when therapy and procedures can no longer prolong survival in these patients, conditions associated with a poor prognosis(1).

In transplants scenario, Brazil has guided behaviors that are incorporated primarily in Latin America and around the world, which highlights the country as a reference in heart transplantation. However, patients listed for heart transplant may remain for a long time on the waiting list, which can result in deaths that could be avoided by transplantation(1) and in a progressive deterioration in quality of life (QOL).

QOL is a concern of health care professionals, especially of those who care for chronic patients with life-limiting diseases, such as HF. QOL can be defined as individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns(2).

Patients with HF on the transplant waiting list show a significant clinical deterioration in QOL while waiting for a donor heart, which is often translated into difficulty performing activities of daily living and increased anxiety and depression(3). However, after transplant, patients have shown better QOL and improved psychosocial functioning as well as low rates of depression and negative feelings, especially among patients aged 65 years or older, which highlights the benefits of the procedure for the elderly population(4). Among younger patients, the literature shows a significant number of patients surviving 20 years or more after heart transplant, which further confirms the procedure as the gold standard treatment for end-stage HF(5).

Among several validated instruments for assessing health-related QOL, the Medical Outcomes Study 36-Item Short-Form Health Survey (SF-36) can be used in the cardiac population because it contains questions that measure patients' perception of their health(6). In Brazil, 3 out of the 19 heart transplant teams that perform this procedure nationwide are located in Rio Grande do Sul, a state where transplantation has gained momentum due to increasing organ donation rates. However, to date, no study has compared the QOL of patients on the heart transplant waiting list to that of patients who have undergone a heart transplant at institutions in this state. Likewise, there has been little research into the topic in this and other regions of Brazil using the SF-36.

In view of the foregoing, and considering that the assessment of the QOL of patients on the transplant waiting list and after surgery is an important predictor of treatment outcome in several clinical conditions, it is therefore relevant to investigate this topic. Aiming to contribute to the existing body of knowledge by providing data from two centers of excellence in the state for heart transplantation, the present study was designed to compare the QOL between patients on the waiting list and heart transplant recipients.

This study will provide health care professionals with data on physical and mental changes experienced by patients while waiting for a donor heart and after the procedure. Knowledge of these parameters may help patient care teams to more clearly understand, follow up and monitor the difficulties encountered, thus becoming able to propose alternatives to achieve better results.

METHODS

This quantitative cross-sectional study of adult patients listed for heart transplant and transplant recipients was conducted at two institutions in Southern Brazil that perform the procedure: Hospital de Clínicas de Porto Alegre (HCPA) and Instituto de Cardiologia – Fundação Universitária de Cardiologia (IC-FUC). Both institutions are located in Porto Alegre, city and capital of Rio Grande do Sul, the southernmost state of Brazil.

All patients on the heart transplant waiting list and those who have undergone a heart transplant and are currently being followed up at the two institutions were invited to participate in the study, regardless of the waiting time and the time of transplant. At HCPA, there were four wait-listed patients and 10 transplant recipients. At IC-FUC, there were six wait-listed patients and 49 transplant recipients, for a total of 10 wait-listed patients and 59 transplant recipients. Because the number of patients was considered small and we intended to include all patients, a sample size calculation was not performed.

Eligible participants were all patients aged 18 years or older who were either on the heart transplant waiting list or had already undergone a heart transplant and were being followed clinically at one of the two institutions. Patients with kidney/liver/lung or systemic comorbidities that could lead to misinterpretation of findings or result in limited life expectancy were excluded from the study.

All eligible patients were approached for data collection during outpatient visits and monthly meetings that occur in the institutions. Data were collected from August to December 2012. Prior to data collection, participants were informed of the study objectives, ensured confidentiality of the responses, and required to provide written informed consent. Patients who agreed to participate first answered a questionnaire on clinical and demographic data, and then the SF-36. Total interview time was 20 minutes.

Two instruments were used. The first aimed to characterize the study population and included sociodemographic variables (such as sex, age, race, socioeconomic status, and education level) and clinical variables (such as HF duration and etiology, comorbidities, pharmacological treatment, survival after transplant, and time on the waiting list).

The second instrument was the SF-36, validated in Brazil(6), which was used to assess patients' perceived QOL. It consists of 11 questions and 36 items divided into eight dimensions: physical functioning (10 items), role-physical (four items), bodily pain (two items), general health (five items), vitality (four items), role-emotional (three items), mental health (five items), and social functioning (two items), and a question to compare current with past (one year ago) perception of health. All raw dimension scores are transformed into a 0-100 scale, where a score of zero is equivalent to "much worse" and a score of 100 is equivalent to "much better".

The study followed the Resolution number 466/12 of the Brazilian National Health Council and was approved by the ethics committees of HCPA (number 66849) and IC-FUC (number 60497). All individual participants included in the study signed an informed consent form twice.

Continuous variables were expressed as mean (SD) or median and interquartile range, and categorical variables were expressed as absolute and relative frequencies. QOL scores were compared between wait-listed patients and transplant recipients using the nonparametric Mann-Whitney test. P-values < 0.05 were considered statistically significant.

RESULTS

Sixty-nine patients were initially identified and considered for enrollment in the study, 10 patients on the heart transplant waiting list and 59 patients who had undergone a heart transplant at one of the two institutions. Among transplant recipients, two were excluded due to renal failure, one refused to participate, and nine patients were unable to attend the visits or meetings because they lived in the countryside. During data collection, one patient was removed from the waiting list and underwent a transplant, being unable to answer the questionnaire, and was also excluded. Thus, 56 patients were included in the final sam-

Table 1 – Sociodemographic and clinical characteristics of the sample. Porto Alegre/RS, Brazil, 2012

Characteristics	n = 56
Group†	
Wait-listed patients	9 (16)
Transplant recipients	47 (84)
Sex, male†	43 (76.8)
Race, white†	42 (75)
Age, years*	55±11
Professional status†	
Retired	33 (59)
On leave	11 (19.6)
Working	12 (21.4)
Marital status, with a partner†	49 (87.5)
Years of study*	9.1±4.4
Living with two or more family members†	28 (50)
HF duration, years*	19.7±10.3
Most common HF etiologies†	
Ischemia	28 (50)
Valve failure	12 (21.4)
Congenital	5 (8.9)
Requiring hospitalization in the past 12 months†	23 (41)
Reason for admission†	
Routine examination	13 (23.2)
Cardiovascular problems	6 (10.7)
Surgical procedure	6 (10.7)
Previous coronary artery bypass grafting†	18 (32.1)
Percutaneous coronary intervention	19 (34)
Comorbidities†	
Systemic hypertension	43 (76.8)
Dyslipidemia	31 (55.4)
Arrhythmia	25 (44.6)
Diabetes mellitus	18 (32.1)
Smoking†	
Abstinent smoker	34 (60.7)
Never smoked	22 (39.3)
Regular physical activity†	23 (41.1)
Number of medications used*	7.7±2.0
Time on the waiting list, months*	6 (3-9)
Survival after transplant, years*	10 (4-13)

Source: Research data, 2012.
*Continuous variables = mean ± SD or median and percentiles.
† Categorical variables = n (%).

ple, 9 (16.0%) wait-listed patients and 47 (84.0%) transplant recipients. The patient with the lowest transplant time had two months of surgery and the patient with the least waiting time was for a month on the list.

Mean age was 55 (SD, 11) years, and 43 (76.8%) participants were men. Ischemia was the most common etiology of HF, found in 28 (50.0%) cases, followed by valve failure in 12 (21.4%) cases. Twenty-three patients required hospital readmission in the past year due to different causes: 13 (23.2%) patients for routine examination, six (10.7%) to undergo a surgical procedure, and six (10.7%) due to cardiovascular problems.

Eighteen patients (32.1%) had already undergone coronary artery bypass grafting and 19 (34.0%) had undergone percutaneous coronary intervention. Regarding comorbidities, 43 (76.8%) patients had hypertension, 31 (55.4%) had dyslipidemia, and 18 (32.0%) had diabetes. Thirty-four patients (60.7%) were former smokers, and 23 (41.0%) reported performing physical activities regularly. The characteristics of the study sample are shown in Table 1.

Regarding the overall QOL score, the mean rank was 16.9 in wait-listed patients and 30.7 in transplant recipients, with statistically significant difference between the two groups (p=0.010). The median of the overall QOL value in patients list was equal to 34(10-48), while in transplant patients, this value was equal to 48(48-68), as shown in Figure 1.

When QOL scores were compared between the two groups, although transplant recipients had higher scores in all eight SF-36 dimensions, four dimensions showed a statistically significant difference between groups: physical functioning, general health, vitality, and social functioning. All other dimensions (role-physical, bodily pain, role-emotional, and mental health) showed no statistically significant differences. In wait-listed patients, physical functioning and general health were the most commonly impaired dimensions (Table 2).

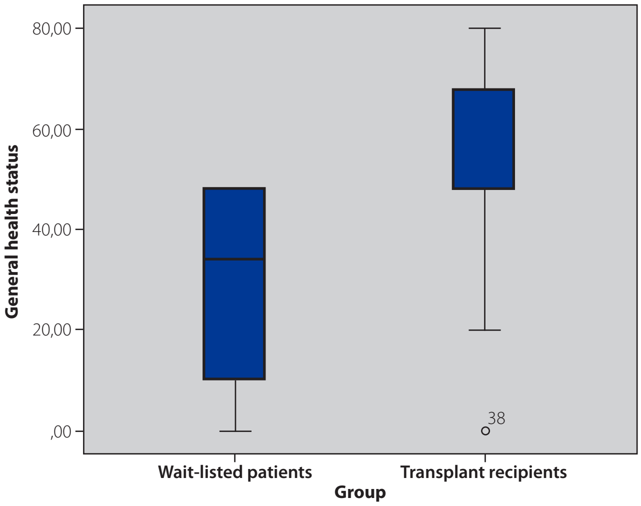

Figure 1 – Boxplot comparison of quality of life values between the two groups. Porto Alegre/RS, Brazil, 2012

Source: Research data, 2012.

DISCUSSION

This study was designed to compare the QOL between patients on the waiting list and heart transplant recipients. The results showed improved QOL scores in transplant recipients compared with patients on the heart transplant waiting list. When analyzing the scores by dimension, items related to physical functioning, general health, vitality, and social functioning were significantly different between groups. All other dimensions (role-physical, bodily pain, role-emotional, and mental health) had higher scores in

Table 2 – Comparison of quality of life scores by dimensions. Porto Alegre, RS/Brazil, 2012.

Dimension	Wait-listed patients*	Transplant recipients*	P-value
Physical functioning	9.5	32.1	< 0.001
Role-physical	22.6	29.6	0.131
Bodily pain	18.2	29.1	0.069
General health	9.1	32.2	< 0.001
Vitality	14.9	31.1	< 0.001
Social functioning	17.6	30.0	< 0.001
Role-emotional	24.8	29.2	0.302
Mental health	24.6	29.2	0.439

Source: Research data, 2012.
*Data are expressed as mean rank.

the group of transplant recipients, but no statistically significant difference was observed.

In the setting of QOL and HF, it is known that HF patients often go through major changes in life patterns and everyday life, becoming unable to perform certain daily tasks due to the signs and symptoms of HF, such as dyspnea on exertion or at rest, orthopnea, fatigue and edema(7). It is also known that, among these patients, the number of hospital readmissions is high. In a study conducted with 303 HF patients, 69% of the sample had been hospitalized with decompensated HF in the past year. Of these, 32% had at least three hospital readmissions and 13.5% were hospitalized more than five times(8).

Despite significant advances in treatment modalities, the prognosis of patients with HF remains guarded(7). For patients who are refractory to medical therapy and have an implanted device, such as a pacemaker, but still require frequent hospital readmissions and remain within an extremely limiting functional class, heart transplantation appears as the only treatment option. However, only a small number of wait-listed patients receive an organ because of the limited number of donors, in addition to strict selection criteria that result in the exclusion of many candidates(9).

In the present study, the median time spent on the waiting list was six months, but some patients waited up to five years for a donor heart. In this group of patients, QOL was significantly reduced compared with the QOL of transplant recipients. In Brazil, a study published in 2009 assessed the QOL of patients awaiting heart transplantation in the city of São Paulo, and the results showed that 17% of patients rated their health as very bad, 44% as bad, and 39% as good(10).

Since 1967, when the first heart transplant was performed, this procedure has been recommended as the treatment of choice for refractory HF. The improvement of surgical techniques, the development of a standardized system for endomyocardial biopsy and the discovery of immunosuppressive drugs have improved the life expectancy of transplant recipients. The median survival after heart transplant has increased to 10 years, and, currently, patients can live for about 20 years post-transplant with better QOL(5,11). These data are consistent with the findings reported in the present study, in which the median post-transplant survival was 10 years, and the patient with the longest survival time survived 23 years after transplant.

Similar results have been reported in the international literature. In a recently published prospective study, 133 patients who survived 20 years or more after heart transplant were evaluated. The mean age at transplant of the 20-year survivors was 43 years, and the survival rates at one, 10, and 20 years post-transplant were 82.7%, 63.9%, and 55.6%, respectively(5).

A recent Polish study showed similar findings for QOL. In that study, 63 transplant recipients answered questions related to their life before and after the transplant. The results demonstrated that average QOL, on a 10-point scale, increased from 3.16±1.47 to 7.60±1.21, with a statistically significant difference between pre- and post-transplant QOL scores. In addition, 59 (93.7%) patients perceived a significant improvement in their QOL after transplant(12). These data reaffirm heart transplantation as a treatment modality capable of improving stability and promoting QOL in HF patients.

Regarding marital status, in the present study, 87.5% of patients were married or had a partner, and 98.2% of patients lived with their partner or with two or more family members. These are important data because it is known that heart transplant patients require great support from their family during preparation for and mainly after surgery, including a complex readjustment of the family dynamics due to the risk of infection and rejection(13).

Preoperatively, adjustments are needed so that the patient is ready to receive a heart when it becomes available for transplant. Postoperatively, there are changes in the patient's and family's daily life functioning due to the need for an adequate place to live, several medications, routine examination, and periodic medical appointments(3). In addition, comorbidities are commonly seen in cardiac patients, requiring the use of other medications and changes in lifestyle, such as those observed in the present study, in which more than half of the patients had hypertension and dyslipidemia, and a significant number of patients had arrhythmia and diabetes mellitus.

It is important to highlight that the goal of transplantation is not only to prolong survival but also to improve QOL and enable patients to return to normal activities. In a Canadian study published in 2010 using the SF-36 to assess pain in 92 heart transplant recipients, the results showed that 46% of patients reported at least mild pain and 21% reported moderate to severe pain(14). Moreover, physical symptoms, such as fatigue, lack of energy, and nervousness, are associated with patients' perceptions after heart transplant and may last more than one year after surgery, which can be a barrier to patients achieving better QOL by affecting their mental, social, and physical well-being(15). These data are in agreement with the present results, which showed no statistically significant difference in bodily pain or role-physical dimensions between the two groups.

The absence of statistical difference in the role-physical dimension is expected, considering that transplant patients often have reduced ability to exercise. In this respect, Brazilian study aimed to evaluate 14 patients' progress four years after cardiac transplant, through the six-minute walk test. Results showed that patients' cardiovascular responses were below the estimated, with a decrease of 11.6% in walking distance when compared with the estimated distance. For these reasons, physical activity should be started early to restore physical capacity, enabling transplanted patients back to perform most of their daily activities(16).

With regard to the role-emotional and mental health dimensions, both also showed no statistically significant difference between the two groups. According to the literature, depressive symptoms are commonly found in transplant recipients and reported as one of the main factors associated with impaired QOL after transplant(17). These symptoms justify the need for interventions to modify negative feelings and thoughts in an attempt to improve QOL.

It is important to note that, although transplant recipients showed higher overall QOL scores and a significant between-group difference was observed in some dimensions, their mean scores remained low. Consistent with these findings, results from a study involving nine transplant recipients in a Brazilian transplant center showed that, after transplant, patients recognized the positive changes brought about by the procedure with regard to clinical symptoms. However, patients reported loss of autonomy and many limitations, which require constant adaptation to post-transplant lifestyle(18).

Following the same reasoning, an Italian study aimed to describe the QOL of 122 patients 10 years after the procedure. Results demonstrated that physical QOL was significantly lower than the expected for the general population, as well as dimensions physical functioning, role-physical, bodily pain, general health, social functioning, and role-emotional. The authors concluded that heart transplantation is associated with a high QOL in the long term, however, factors affecting QOL should be identified in order to search for the best treatment(19). These data are similar to the present study and may explain why the scores did not exceed 32.1 in the post-transplant group.

It is known that only a few patients return to work after transplant, and that clinical variables, such as pain and depression, can be a limiting factor(20). Therefore, the findings of the present study allow us to infer that close follow-up by a multidisciplinary team may improve patients' understanding of factors associated with their condition, thus facilitating their return to normal activities and minimizing their suffering both while waiting for a donor heart and after transplant.

Limitations

A limitation of this study was the use of a single QOL measure. Also, the evaluation of the same patient at different stages of follow-up could have yielded different results. In view of this, further studies with thorough follow-up of both groups are warranted to help patients better understand the source of their distress, thus opening up the possibility of obtaining better QOL scores pre- and post-transplant.

CONCLUSION

For patients who have undergone a heart transplant, QOL is significantly higher than that of patients on the transplant waiting list. Physical functioning, general health, vitality and social functioning were the best-scoring dimensions for transplant recipients. These results can be encouraging for patients who are still on the waiting list, because they reflect the benefits of transplant and its positive impact on health-related QOL. Despite all the risks involved in heart transplantation, this surgical approach, when successfully performed, enables patients to improve their QOL.

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Corresponding author:
Eneida Rejane Rabelo-Silva
E-mail: eneidarabelo@gmail.com

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