Brazilian Journal of TRANSPLANTATION

ARTIGO ORIGINAL

Quality of Life of Heart Transplant Patients During the COVID-19 Pandemic

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https://doi.org/10.53855/bjt.v25i3.455_in

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Section Editor
Ilka de Fátima S. F. Boin

Received
Mar. 11, 2022

Approved
Jul. 30, 2022

Conflict of interest
Nothing to declare.

How to Cite
Ferreira JML, Poltronieri NVG. Quality of Life of Heart Transplant Patients During the COVID-19 Pandemic. BJT. 2022;25(3):e0622. https://doi.org/10.53855/bjt.v25i3.455_in

eISSN
2764-1589

Abstract: The objective of this study was to evaluate the quality of life of heart transplant recipients during the pandemic of COVID-19 through a cross-sectional, descriptive and quantitative study. Individuals under treatment in a tertiary cardiology hospital in the city of São Paulo (SP) were included. The sample was 40 transplanted individuals with a time frame of more than one year and age over 18 years. The instrument was the World Health Organization Quality of Life questionnaire (WHOQOL-BREF) from October 2021 to January 2022. After data collection, a compilation was made with descriptive analysis of the variables and calculation of the instrument, obtaining as a final result the calculation of the mean and standard deviation. The results highlighted the importance of improvements in several facets of each domain and public issues related to public transportation and daily life safety. It was possible to observe numerous difficulties in relation to the availability and ease of access in various sectors, a situation that also led to changes in the perception and quality of health as a whole, with sudden changes in the population's daily lives. The study was satisfactory, making it possible to evaluate points of improvement in the quality of life of heart transplant recipients during the pandemic of COVID-19.

Keywords: Heart Transplantation; Quality of Life; Coronavirus.

INTRODUCTION

COVID-19, caused by the new coronavirus (SARS-CoV-2), is a severe acute respiratory syndrome and became a pandemic in March 11, 2020, with high rates of lethality, especially in individuals with chronic diseases. Numerous are the complications and daily difficulties for the population, affecting quality of life as a whole. Based on the clinical and life pattern of heart transplant recipients, with greater immune susceptibility and high prevalence of postgrafting comorbidities,[1] of which immunosuppression caused by the use of corticosteroids after heart transplantation further predisposes the risk of contamination and complications by the SARS-CoV-2 virus infection, the daily life of these patients is affected.[2]

With the COVID-19 pandemic, there was both a reduction in transplant surgeries and difficulty in outpatient follow-up, transportation, and access to tests and medications, which significantly impacts the postcardiac transplant treatment process, that is a therapeutic indication for patients with refractory heart failure.[3] Despite the decrease in heart transplants during the pandemic, there is greater concern with heart transplant recipients because of their greater predisposition to viral and bacterial infections, with the possibility of graft rejection and even death.[4]

These circumstances lead us to the need to evaluate the enhancement of people's quality of life and, in this context, also that of heart transplant recipients, because of

their greater immunological vulnerability, constant dependence on medical assistance from the health team, and the availability of services that facilitate this treatment and result in a satisfactory quality of life.[5]

The evaluation and follow-up after heart transplantation are essential for the continuity of treatment in the rehabilitation and recovery of these patients.[6] It requires adaptations in lifestyle, psychosocial, emotional, and coping means, and this has a direct impact on drug and nondrug adherence, which impacts the life process and the fact of having a successful transplant in the long term.[7]

Quality of life will reflect on the perception and self-esteem of individuals, involving a series of aspects, such as their position in society regarding cultural and social contexts, functional capacity, socioeconomic level, religiosity, self-care, lifestyle, satisfaction with the environment in which they live their daily activities, and their health status.[8] The evaluation of quality of life encompasses the individuals' health in a complex way, for it involves, besides physical health, social, psychological, cultural, and environmental aspects.[9]

Due to some weaknesses and difficulties in assessing quality of life by means of instruments, the World Health Organization (WHO) developed the WHOQOL-100 instrument, which assesses a person's perception of their life position in the cultural context, their expectations of life, health and interpersonal relationships, standards, and concerns.[10]

Because of the complexity of the WHOQOL-100—there are 100 items to assess—the WHO created the shortened version of the WHOQOL-100, defined and developed by the WHO Quality of Life Group with the objective of assessing quality of life in general and its use in different cultures. The World Health Organization Quality of Life (WHOQOL-BREF)[11] was validated in Brazil in 2000 and is usually used to assess the outcome of studies with workers, patients with chronic and psychiatric diseases and the elderly.[11] It is a questionnaire composed of 26 facets, two of which assess quality of life in general and the other 24 divided into four domains:

- Physical: physical pain, treatment, energy, mobility, sleep, daily activities, and work capacity;
- Psychological: enjoyment of life, meaning of life, concentration, physical appearance, self-satisfaction, and negative feelings;
- Social relationships: personal relationships, sex life, and support from friends;
- Environment: safety in daily life, healthy environment, financial resources, available information, leisure activities, housing, access to health services, means of transportation.[12]

Therefore, facing the pandemic scenario of COVID-19, which has affected the daily life of the entire world population, it is necessary to question how the quality of life of heart transplant patients is, in what way life was affected in the continuity of treatment, due to the decrease of appointments, access restrictions, transportation and leisure, daily insecurities, behavioral and psychological changes, with social and family distancing. Thus, the objective of this study was to evaluate the quality of life of heart transplant patients during the pandemic of COVID-19 using the WHOQOL-BREF instrument.

METHODS

This is a cross-sectional, descriptive study with a quantitative approach.

For construct and criterion validation, individuals under treatment at a tertiary cardiology referral hospital in the city of São Paulo (SP) were included in the study. The sample is nonprobabilistic and by convenience, composed of patients who underwent heart transplantation with time greater than one year and age over 18 years.

The participants were selected during the waiting period for the outpatient consultation. The instrument was chosen to be applied rather than self-completed, lasting an average of 15 minutes per individual. The variables analyzed were qualitative, such as gender and marital status, and quantitative, such as age, education, time since transplantation and the study variables, involving the physical, psychological, social relations and environment facets of the WHOQOL-BREF instrument.

The study population in the period from October 2021 to January 2022 was approximately 60 individuals, an average of 15 patients per month, who fit the established criteria, also considering the returns of the same participant in the same month. Slovin's formula—$N/(1+N\times e^2)$—with a 4% margin of error was used. The result for the sample size calculation according to the population was 55 participants, but a sample of 40 participants was used to validate the construct. Study participants were those individuals who agreed to participate in the research by having themselves and/or their caregivers sign the informed consent form.

The instrument to assess the quality of life of the heart transplant patients in the study was the WHOQOL-BREF structured questionnaire (Table 1), which is the shortened version of the WHOQOL-100—the first created with the purpose of assessing quality of life in general and its use in different cultures. The WHOQOL-BREF is composed of 26 facets, two of which assess quality of life in general and the other 24 divided into four domains: physical, psychological, social relations, and environment. The objective of the instrument is to evaluate the individual in the last two weeks, and the instrumentation of the answers is formalized as a Likert-type scale, characterized with levels of intensity, capacity, frequency, and satisfaction, and scored from 0 to 100, being expressed as a mean from 1 to 5, according to the calculations in each domain. Higher averages suggest better quality of life.[7]

Table 1. Domains and facets of the World Health Organization Quality of Life (WHOQOL-BREF).

Domains	Facets
I Physical	Physical pain and discomfort, treatment, energy and fatigue, mobility, sleep, daily activities, and work capacity.
II Psychological	How to enjoy life, meaning of life, concentration, physical appearance, self-satisfaction and negative feelings, personal beliefs, spirituality.
III Social relationships	Personal relationships, sex life, and support from friends.
IV Environment	Safety in daily life, healthy environment, financial resources, available information, leisure activities, housing, access to health services, means of transportation.
V General	Perceived quality of life and health satisfaction.

The WHOQOL-BREF instrument is calculated according to the domains: question (Q) 1, perception of quality of life (average score 1 to 5); and Q2, satisfaction with health (average score 1 to 5). The other domains are added to the questions and divided by the number of facets, according to the questions:

- Physical: Q3, Q4, Q10, Q15, Q16, Q17, Q18/7;
- Psychological: Q5, Q6, Q7, Q11, Q19, Q26/6;
- Social relations: Q20, Q21, Q22/3;
- Environment: Q8, Q9, Q12, Q13, Q14, Q23, Q24, Q25/8.

The rating is done according to the average of each domain, as: needs improvement (when 1 to 2.9), fair (3 to 3.9), good (4 to 4.9), and very good 5.[10]

After data collection, a compilation was made with descriptive analysis of the variables such as gender, age, marital status, education, etiology and time of transplantation, and variables from the instrument used, obtaining the results as required for the interpretation and calculation of the WHOQOL-BREF scale, which were tabulated in a Microsoft Excel spreadsheet and achieved as a final result the calculation of the mean and standard deviation (SD) of each question involving all facets.

The study was approved and authorized by the Research Ethics Committee, respecting Resolution No. 466/2012 of the National Health Council, and Plataforma Brasil, with Certificate of Ethics Appreciation Submission (CAAE) 50179921.4.0000.5462.

RESULTS

After organizing and analyzing the data, sociodemographic information was stipulated, including the variables age, gender, marital status, education, time of transplantation, and underlying pathology.

The study was performed with 40 individuals (Table 2), 21 (52.5%) men and 19 (47.5%) women. The age ranged from 26 to 81 years, with a predominance of 50 to 60 years, corresponding to 17 (42.5%) transplanted patients, followed by 61 to 81 years, with 12 (30%), and with a lower frequency of 26 to 48 years, with 11 (27.5%) patients. Of the 40 participants, most were married, a total of 26 (65%), 5 (12.5%) were single, 5 (12.5%) were divorced, 2 (5%) were in a stable union, and 2 (5%) were widowed. About the number of children, a greater predominance of two children was perceived, corresponding to 13 (32.5%) patients, followed by three children by 8 (20%) participants, four children, one child and none by 5 (12.5%) patients equally, and, with lower prevalence, five and seven children by 2 (5%) patients in each category. As for the level of education, 12 (30%) of the 40 study participants had some elementary school education, 10 (25%) had elementary school education completed, 6 (15%) pointed out some high school education, followed by 4 (10%) with high school education completed, 4 (10%) with college education completed, and 4 (10%) with some college education.

Table 2. General sociodemographic distribution of the participants.

Variables		N	%
Sex	Female	19	47.5
	Male	21	52.5
Age (years)	26-48	11	27.5
	50-60	17	42.5
	61-81	12	30.0
Marital status	Married	26	65.0
	Single	5	12.5
	Divorced	5	12.5
	Stable union	2	5.0
	Widower	2	5.0
Education	Elementary school completed	10	25.0
	Some elementary school	12	30.0
	High school completed	4	10.0
	Some high school	6	15.0
	College degree completed	4	10.0
	Some college	4	10.0

In Table 3, the time of transplantation ranged from 2 to 18 years, with the highest prevalence from 2 to 8 years, with 29 (72.5%) transplanted patients, followed by 9 to 11 years, corresponding to 7 (17.5%) patients, and, with the lowest percentage, from 12 to 18 years, a total of 4 (10%) transplanted patients. Regarding the type of underlying pathology of the transplanted patients, idiopathic dilated cardiomyopathy was the most prevalent, with a total of 18 (45%) of the 40 patients, followed by Chagasic cardiomyopathy, with 12 (30%) individuals; valve cardiomyopathy, with a total of 5 (12.5%) patients; and hypertrophic cardiomyopathy, with 2 (5%) patients.

Table 3. Distribution of participants on timing of transplantation and cardiac etiology.

Variables		N	%
Time since transplantation (years)	2-8	29	72.5
	9-11	7	17.5
	12-18	4	10.0
Cardiac etiology	Idiopathic dilated	18	45.0
	Chagasic	12	30.0
	Valvar	5	12.5
	Hypertrophic	2	5.0

Table 4 presents the means and SD in the facets of each domain of the WHOQOL-BREF questionnaire. Q1 and Q2, about quality of life and health, correspond to the overall quality of life. The first question about the perception of transplanted patients about quality of life had a mean of 4.22, considered good (4 to 4.9), and SD = 0.43. The second question, about health quality, also had a good average, 4.15, and SD = 0.42. The two overall questions were generally seen as good, with no need for improvement.

Table 4. Distribution of the analysis of overall quality of life and facets of the World Health Organization Quality of Life scale (WHOQOL-BREF).

Domains	Facets	Average	Standard deviation
General	1. Quality of life	4.22	0.43
	2. Health	4.15	0.42
Physical	3. Physical pain	1.85	0.92
	4. Treatment	3.9	0.54
	10. Energy	3.72	0.84
	15. Mobility	4.37	0.74
	16. Sleep	3.47	0.75
	17. Daily activities	4.0	0.55
	18. Work capacity	3.42	0.67
Psychological	5. Enjoying life	3.52	0.67
	6. Meaning of life	4.52	0.50
	7. Concentration	4.1	0.70
	11. Physical appearance	4.22	0.57
	19. Self-satisfaction	4.17	0.59
	26. Negative feelings	1.6	0.81
Social relationships	20. Personal relationships	3.8	0.72
	21. Sex life	3.77	0.83
	22. Support from friends	3.7	0.91
Environment	8. Safety in daily life	3.72	0.84
	9. Healthy environment	4.07	0.65
	12. Financial resources	3.27	0.70
	13. Information available	3.95	0.71
	14. Leisure activity	3.27	0.78
	23. Habitation	4.3	0.51
	24. Access to health services	4.47	0.55
	25. Means of transportation	3.95	0.71

In the physical domain, which is formed by questions referring to physical pain, treatment, energy, mobility, sleep, daily activities, and work capacity, a more heterogeneous average was noticed. In the third question, related to physical pain, the first one had a mean = 1.85, showing not to refer to physical pain frequently. In this question, it is considered a favorable average, but the high SD of 0.92 indicates oscillation among the answers. In the other questions, the average ranged from regular to good: treatment (3.9), energy (3.72), sleep (3.47) and work capacity (3.42)—all regular, with a tendency to need improvement. Mobility (4.37) and daily activities (4) had good averages. The SD of the domain had homogeneous values, except for pain.

In the psychological domain, composed of questions such as enjoying life, meaning of life, concentration, physical appearance, self-satisfaction, and negative feelings, regularity and good averages, ranging from 4.1 to 4.52, were observed: meaning of life (4.52), concentration (4.1), appearance (4.22), and self-satisfaction (4.17). There was a difference in the question about enjoying life, with a regular average of 3.52, with room for improvement. Most said they did not feel negative feelings, obtaining a mean = 1.6. The SD of the psychological domain ranged between 0.50 and 0.81.

In the social relationships domain, involving personal relationships, sex life, and support from friends, regular averages stood out, ranging from 3.7 to 3.8, with a need for improvement, with a SD ranging from 0.72 to 0.91.

In the last domain of the WHOQOL-BREF scale, environment, the average ranged from fair to good (3.27 to 4.47). Leisure activities and financial resources stood out with the worst averages, both with a mean = 3.27, followed by safety of daily life, with a mean = 3.72. As for the facets ease of access to information and access to means of transportation, both public and private, the results were regular, but closer to the good average, both also with the same average, 3.95. Most participants said they live in a good housing (4.3) and a favorable and healthy environment (4.7). Regarding the access to health services, taking into account the hospital where they are treated and the basic health units, the average was good, 4.47, also considering the access to transportation.

In general, the results obtained highlighted the importance of improvements in several facets of each domain, such as physical, psychological, social relations, public issues related to public transportation, and safety of daily life. The SD of the domain ranged from 0.51 to 0.84.

DISCUSSION

Considering the results obtained by the study on quality of life of heart transplant patients during the pandemic of COVID-19, the largest population analyzed was male, with a predominance of age from 50 to 60 years. The most recurrent time of transplantation was two to eight years, and the most present etiology, dilated cardiomyopathy.

The predominance of these variables also influences the quality of life of heart transplant recipients, taking into account that age predisposes to a greater dependency and more associated comorbidities, which have a direct impact on the transplantation and propitiate polypharmacy, which also hinders drug compliance. The two-year transplantation time is still considered a recent time, with adaptations, longer follow-ups, which reflects in the quality of life of the heart transplanted patients.

Regarding the variables of the instrument used, a pattern of regular to good quality was found, involving the physical, psychological, social relations and environment domains, according to the answers described by the participants. The WHOQOL-BREF questionnaire tool allows the evaluation not only of physical and psychological health context, but also the social context and the individual's perception of their quality of health and of life in general. In other words, it allows the measurement of several issues directly or indirectly related to public management, such as safety, healthy environment, leisure activities, housing, available information, access to health services and means of transportation.

During the COVID-19 pandemic, numerous difficulties regarding availability and ease of access in various sectors could be observed, a situation that also led to changes in the perception and quality of health as a whole, with sudden changes in the population's daily lives. In the study, the social relationships domain of the transplanted patients was, during the COVID-19 pandemic, the one that remained more in the regular average, because of the decrease of relationships among friends and family. Other relevant issues were the possibility and availability to practice leisure activities, with the transplanted patients of the study referring to a decrease and even no practice of any leisure activity, due to the restrictions of the pandemic and the reduction of financial resources. These problems impact significantly on psychological and behavioral issues, altering the quality of sleep, the ability to work and how these individuals enjoy life.

The WHOQOL-BREF, which is a tool of easy application and developed to be used in several population profiles, has some limitations, because the answers are subjective and cannot be measured or proved, thus having biases. Despite this, the instrument can be of support to public assistance and management, of evaluation in areas of physical, psychological, social, financial, and social relationships of patients, and useful in the management of health as a whole, not only regarding the disease.

CONCLUSION

The present study enabled the perception of the quality of life of heart transplant patients during the pandemic of COVID-19 not only of health and disease, but also of all the social, economic, psychological, and social relations issues, which reflect in a general way in the treatment process and in how this individual will manage to maintain a standard of quality of life that provides health.

The results of the study were satisfactory. The WHOQOL-BREF instrument enables the assessment of points where there is need for improvement in the quality of life of heart transplant recipients during the COVID-19 pandemic. In addition, it is a low-cost, efficient, easily applied and validated individual perception tool in several countries.

AUTHORS' CONTRIBUTION

Substantive scientific and intellectual contributions to the study: Ferreira JMF, Poltronieri NVG. **Conception and design:** Ferreira JML, Poltronieri NVG. **Technical procedures:** Ferreira JML, Poltronieri NVG. **Data analysis and interpretation:** Ferreira JML, Poltronieri NVG. **Statistical analysis:** Ferreira JML, Poltronieri NVG. **Writing of the manuscript:** Ferreira JML. **Critical revision:** Ferreira JML, Poltronieri NVG.

AVAILABILITY OF RESEARCH DATA

All data were generated or analyzed in the present study.

FINANCING

Not applicable.

ACKNOWLEDGEMENTS

Not applicable.

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