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Quality of life in heart transplant candidates

Qualidade de vida dos candidatos a transplante de coração

Renata Almeida Barros HELITO[1], João Nelson Rodrigues BRANCO[2], Maria D'INNOCENZO[3], Regimar Carla MACHADO[4], Enio BUFFOLO[5]

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Abstract

Objective: **To assess the quality of life of patients with refractory heart failure disease as candidates for heart transplant.**

Methods: **A transversal, descriptive and prospective study with 18 adult patients, with mean age of 52 years under pre-transplantation outpatient follow-up at educational and public hospital in São Paulo town. The quality of life was assessed by reference to "The Medical Outcomes Study 36-item Short-Form Health Survey" (SF-36) generic questionnaire in order to assess the aspects in relation to the function, dysfunction, physical and emotional uneasiness.**

Results: **According to this group, 14 (77.8%) of these patients were male and four (22.2%) female; 14 (77.8%) of them were classified as functional class IV and four (22.2%) as functional class III (New York Heart Association); 17 (94.4%) of them were at stage D and one (5.6%) at stage C (American Heart Association/American College of Cardiology). The mean results obtained from the assessment of SF-36 scales were: functional capacity 38%, pain 49%, health general condition 49%, vitality 39%, social aspects 53%, emotional aspects 43% and mental health 54%.**

Conclusion: **The quality of life of patients presenting terminal heart failure is considered to be very bad; it is likely to be worse than in many other more common morbid entities. Both mental and social aspects are least affected, on the other hand the vitality and functional capacity are the most affected.**

Descriptors: **Quality of life. Sickness impact profile. Cardiac failure. Heart transplantation.**

Resumo

Objetivo: **Aferir a qualidade de vida de pacientes com insuficiência cardíaca refratária, inscritos como candidatos a transplante de coração.**

Métodos: **Estudo prospectivo, descritivo, transversal de 18 pacientes, com média de idade de 52 anos, em acompanhamento ambulatorial pré-transplante, de um hospital público e vinculado ao ensino do Município de São**

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1. Master's Degree Student in Sciences – Cardiovascular Surgery Department (Nursing Auditor).
2. Full Professor in Cardiovascular Surgery of UNIFESP/EPM. (Adjunct Professor, Full Professor of the Discipline of Cardiovascular Surgery of the Surgery Department of UNIFESP/EPM.
3. PhD in Nursing by UNIFESP/EPM. (Adjunct Professor, PhD of the Discipline of Health Public and Administration applied to Nursing of the Nursing Department of UNIFESP/EPM.
4. Master's Degree in Sciences – Cardiovascular Surgery Department of UNIFESP/EPM. (Professor of the Nursing Course of Vale do Paraíba University – UNIVAP, São José dos Campos – SP).
5. Full Professor. Titular Professor of the Discipline of Cardiovascular Surgery of the Surgery Department of UNIFESP/EPM.

This study was carried out at Post-Graduation Program in Cardiovascular Surgery of UNIFESP/EPM. Study carried out at Cardiac Surgery Outpatient of São Paulo Hospital.

Correspondence address:
Renata Almeida Barros Helito R. José Antonio Coelho, nº 661, apto. 62 - CEP 04011-062 - Vila Mariana São Paulo - SP
Fone: (11) 5571-6566
E-mail: helitorenata@gmail.com

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Paulo. A qualidade de vida foi avaliada por meio do questionário genérico *The Medical Outcomes Study 36-item Short-Form Health Survey* (SF-36), com a finalidade de avaliar aspectos relativos a função, disfunção, desconforto físico e emocional.

***Resultados:* Dessa amostra, 14 (77,8%) pacientes eram do sexo masculino e quatro (22,2%), do sexo feminino; 14 (77,8%) dos pacientes foram classificados segundo tipo funcional IV e quatro (22,2%) em tipo funcional III (*New York Heart Association*); 17 (94,4%) encontravam-se em estágio D e um (5,6%) em estágio C (*American Heart Association/ American College of Cardiology*). As médias obtidas na avaliação das escalas do SF-36 foram: capacidade funcional 38%, dor 49%, estado geral de saúde 49%, vitalidade 39%, aspectos sociais 53%, aspectos emocionais 43% e saúde mental 54%.**

***Conclusão:* A qualidade de vida dos pacientes com insuficiência cardíaca terminal é considerada muito ruim; provavelmente pior que em muitas outras entidades mórbidas mais comuns. Os aspectos, social e mental são os menos afetados, sendo os mais comprometidos, a vitalidade e a capacidade funcional.**

***Descritores:* Qualidade de vida. Perfil de impacto da doença. Insuficiência cardíaca. Transplante de coração.**

INTRODUCTION

Cardiac insufficiency (C.I.) is acknowledged worldwide as a public health problem due to the increasing number of cases arising every year. In the last decade, CI became one of the main problems in public health, causing a source of concern to define health policies in Brazil [1].

CI can be defined as a clinic syndrome in which a structural or functional heart disorder causes decreasing in capacity of the ventricle to eject and/or fill with blood during physiological filling pressure [2].

Cardiac affections are number one as cause of death among the population and CI has become common [3]. CI prevalence is growing, resulting from the increase of Brazilians' life expectation and greater efficiency of new medicine for the treatment, thus prolonging life [4].

In the 1990s, there was an evolution of clinical and surgical advancements at treating patients with CI in more advanced stages, modifying in this way, the morbidity and mortality related to the illness.

During this period, new classes of medicine came upon of which were assessed after innumerable multicentral studies and that confirmed their benefits, permitting not only a longer life after the illness, but also an improvement of the patients' quality of life (Q.L.) [5]; nevertheless, recognition, fast treatment and, when possible, prevention of the factors that cause or worse CI are crucial when handling the patient.

The increase of survival with the treatment has been shown for each stage of the illness, from dysfunction of the asymptomatic left ventricle to severe symptomatic CI [6], Implementation of the therapeutic arsenal seeks not only to increase life after the illness, but also to improve the patient's QL

The term QL started to be used in the United States after World War II intending to describe the effect generated by acquiring technology in people's lives. Years later, QL started to be considered as a parameter to be valued at improving advancements in the health and education areas [7].

It is not easy to define QL. It is an intimate feeling of comfort, well-being or happiness at performing one's physical, intellectual and psychic function, within one's family's reality, at work, values of a community to which one belongs, and that only the oneself can assess [8].

Despite therapeutic implementation to treat CI in the last few years, in the more advanced cases of the illness - called CI in terminal phase - the results are not encouraging, reaching high mortality rates in few months. CI in terminal phase is understood as a patient with expressive limitations of his activities, whereas the classic treatments and the interventional procedures performed do not allow to prolong these patients' lives [1]. In this phase, the only therapeutic option to revert the status and improve QL is heart transplant (HT). Classic signs of refractory cardiac insufficiency are described by several authors [3,6,9].

HT, before considered "a fantastic speculation for the future", is today unquestionably accepted no longer as an experimental procedure, but as an effective method to treat hopeless patients, without the pleasure or satisfaction of a healthy and worthy existence or, even worse, running the risk of losing their greatest asset: life [10].

Despite the restructuring of the organ and tissue transplant system in Brazil, the increasing number of transplant centers and performed transplants, balance between the number of donations and demand of receivers has not happened. This situation makes the patient stay more time in the transplant waiting list, worsening the clinic status, decadence of his physical and psychological condition and QL; increasing surgical risk and possibly leading to death.

In this way, the aim of this study was: to check the quality of life of patients with refractory cardiac insufficiency, enrolled as heart transplant candidates, by means of a standardized and complemented questionnaire (SF-36). Possibly, in the future, it can be an instrument to compare with other populational groups with cardiopathies or other illnesses.

METHODS

It is a prospective, descriptive, exploratory and transversal study, with a quantitative approach. After approval from the Research Ethics Committee of the Federal University of São Paulo – Paulista School of Medicine (UNIFESP – EPM), respecting Resolution Nº 196/96 of the Ministry of Health, data collection began, which took place at the Cardiovascular Surgery Outpatient Clinics of a public hospital related to teaching in the City of São Paulo, from March 11 to May 20, 2005.

The sample consisted of 18 patient candidates to receive a heart transplant. Inclusion criteria were: all patients that were enrolled in the heart transplant waiting list during the period of the survey, 18 years of age or over, regardless gender, besides accepting to participate in the study, signing a written informed consent. Exclusion criterion was to not accept to participate in the study.

Data were collected by means of individual interviews, and an instrument already validated and translated into Portuguese was chosen to be used, a generic questionnaire to assess quality of life: *The Medical Outcomes Study 36–item Short –Form Health Survey*, translated by Ciconelli, in 1997 [11], commonly called SF-36, whose purpose is to reflect the impact of an illness on lives of patients in a large variety of populations.

In the pre-test phase, in which patients filled out the instrument, it was observed they were confused facing the variables of each question and ended up answering randomly; due to this fact, the interview method was chosen.

Several statistical methods were used to tabulate and analyze the questionnaire applied to collect data. For those referring to social-demographic variables, percentages and simple frequencies were used.

The sample of this study consisted of 18 patients in the heart transplant waiting list of the Cardiovascular Surgical Outpatient Clinics of the referred hospital. Social-demographic characterization of the interviewed patients is presented in Tables 1 and 2. Patients' mean age was 52, varying from 35 to 67. Most were men (14 patients; 77.8% of the total), whereas 10 (55.6%) married, four (22.2%) in concubinage and three (16.7%) single. Regarding education, 13 (72.2%) graduated from middle school, followed by two (11.1%) graduated from high school and three (16.7%) graduated from college.

Table 1. Age distribution of patients in the heart transplant waiting list.

	Minimum	Middle	Maximum	Average	Standard Deviation	#
Age (years)	35	53	67	52.5	9.1	18

Table 2. Patient distribution according to social-demographic variables.

GENDER	n°	%
Female	4	22.2
Male	14	77.8
TOTAL	18	100
Education	n°	%
Middle School	13	72.2
High School	2	11.1
University	3	16.7
TOTAL	18	100
Maital Status	n°	%
Married	10	55.6
Divorced	1	5.6
Concubinage	4	22.2
Single	3	16.7
TOTAL	18	100

Regarding the instrument chosen to assess the quality of life of patients in the heart transplant waiting list, the data intended to analyze the Quality of Life according to answers given by patients through *The Medical Outcomes Study 36-item Short-Form Health Survey* (SF-36) questionnaire and presented in Tables 3, 4, 5 and 6. In Table 3 we observe the current health classification that seven (38.9%) report as "good", eight (44.4%) patients classify their health as "bad" and three (16.7%) as "very bad". Comparing their current health condition to that one year ago, three (16.7%) report it being "much better now", four (22.2%) refer to it as "a little better now", three (16.7%) as "a little worse now" and three (16.7%) inform that their health "presented no changes in one year". On the other hand, five (27.8%) patients classified their health as "much worse now" than a year ago.

Table 3. Relative and simple frequency distribution of the SF-36 questions related to the patient's current and one year before health status.

In general, you would say your health is	N	%
good	7	38.9
bad	8	44.4
very bad	3	16.7
Total	18	100
How would you classify your general health, compared to one year ago?	N	%
much better now	3	16.7
a little better now	4	22.2
almost the same	3	16.7
a little worse now	3	16.7
much worse now	5	27.8
Total	18	100

In Table 4, we observe an evaluation of physical performance capacity: Fourteen (77.8%) patients informed "being difficult to perform vigorous activities", three (16.7%) "being a little difficult" and one (5.6%) "not being difficult". When describing activities that demand physical vigor – picking up and carrying groceries, climbing several staircases, climbing one staircase, bending down, kneeling, walking more than 1 km, walking several blocks, walking one block, taking a shower or getting dressed – patients stated at least one or more activities in which it was difficult to perform.

In Table 5, we can observe that the occurrence of problems at work resulting from some emotional problem, "yes" was answered by 10 (55.6%), "had decreased the amount of time dedicated to work" was answered by 11 (61.1%) patients who said they "had done less tasks than they would like", and 10 (55.6%) said they "had not worked or done any kind of activity with so much care as they generally did".

In Table 6, we can observe that the question about the illness interfering in normal social activities, regarding family, neighbors, friends or in group, six (33.3%) patients answered that "there was no interference" 3 (16.7%) "slightly", one (5.6%) reported "moderately" and four (22.2%) said there was "much interference" or "sometimes extreme".

Table 4. Relative and simple frequency distribution for question related to difficulty in performing activities.

Due to your health, do you find it difficult to perform these activities? In this case, how much?		Yes. Very difficult	Yes. A little difficult	No. Not any difficulty	Total
Difficulty at vigorous activities	n	14	3	1	18
	%	77.8	16.7	5.6	100.0
Difficulty at moderate activities	n	10	6	2	18
	%	55.6	33.3	11.1	100.0
Difficulty at lifting or carrying groceries	n	7	6	5	18
	%	38.9	33.3	27.8	100.0
Difficulty at climbing several staircases	n	14	2	2	18
	%	77.8	11.1	11.1	100.0
Difficulty at climbing one staircase	n	3	11	4	18
	%	16.7	61.1	22.2	100.0
Difficulty at activities such as bending down or kneeling	n	8	8	2	18
	%	44.4	44.4	11.1	100.0
Difficulty at walking more than 1 km	n	9	6	3	18
	%	50.0	33.3	16.7	100.0
Difficulty at walking several blocks	n	12	2	4	18
	%	66.7	11.1	22.2	100.0
Difficulty at walking one block	n	3	7	8	18
	%	16.7	38.9	44.4	100.0
Difficulty at taking a shower or getting dressed	n	4	4	10	18
	%	22.2	22.2	55.6	100.0

Table 5. Relative and simple frequency distribution for SF-36 question.

In the last 4 weeks, have you had any of the following problems with your work or other daily activity as consequence of any emotional problem (like feelingdepressed or anxious)?		Yes	No	Total
Have you decreased the amount of time you dedicated to your work or other activities?	n	10	8	18
	%	55.6	44.4	100.0
Have you performed less tasks than you would like to?	n	11	7	18
	%	61.1	38.9	100.0
Have you not worked or not performed any of the activities with as much care as you generally do?	n	10	8	18
	%	55.6	44.4	100.0

Table 6. Relative and simple frequency distribution SF-36 question related to the interference in normal social activities regarding family, neighbors, friends or in group.

Interference in normal social activities, regarding family, neighbors, friends or in group	N	%
no way	6	33.3
slightly	3	16.7
moderately	1	5.6
a lot	4	22.2
extremely	4	22.2
Total	18	100

DISCUSSION

CI is a common syndrome and a progressive condition that invariably leads to chronicity [5]. By implementing the therapeutic arsenal, many patients can be benefited; however, a small part of the population affected by this illness will inevitably be included in the lists of transplants. Social assessments are elaborated in cardiac transplant programs intending to verify the occurrence of the most adverse factors that might stop the inclusion of patients in these programs. By performing interviews, it is intended to identify the patient's social status by classifying some categories extracted from daily life, structured in: acceptability, family dynamics, access and social-economic situation [12].

In our country, according to data from the Brazilian Organ Transplant Association (A.B.T.O.), during 2006, there were 310 patients waiting for a heart and 73 registered teams [13]; few teams had more than 20 patients on their list, whereas most had three or four registered patients. In this way, it is understandable why this study consisted of only 18 patients, which was the number of those enrolled at the institution when the survey was performed.

In the scientific community, several researchers evaluate patients' life after the cardiac illness; however, it is observed that there are few studies discussing QL, whereas it is an important factor for maintaining human dignity.

To some people, prolonging life is not a condition as important as the quality of the life they will have. As one of our patients said: *"Doctor, I don't need to live much, but I want to live well the little life I still have"*. Evaluating QL becomes a challenge and preoccupation of all those who worry about the well-being of people [14]. In the last years, one of the greatest developments in the health field, has been recognizing the importance of the patient's point of view regarding his illness, as well as monitoring the quality of the therapeutic means used [15].

Regarding age, patients in this study varied between 35 and 67, with a mean of 52. These results are compatible with DATASUS data that informs that the largest number of hospital stay due to CI occurs with patients of age 60 or over, followed by patients in the 20 – 59 age range [16].

The studied population consisted of 14 (77.8%) men and four (22.2%) women, but it seems that gender, as a prognostic factor, is not clear in the literature [17].

Hence the fact that the patients filled out the instruments randomly during the pre-test phase by being confused with the variables of each question, this fact is probably due to their little education, whereas 13 (72.2%) finished middle school, two (11.1%) finished high school and three (16.7%) had a college degree. Education is important to follow and continue the treatment; knowing how to read, write and interpret are decisive factors to understand instructions of the proposed treatment, exams to be performed and care to be taken. Besides this, it is fundamental that the patient is able to understand and assimilate instructions, which demands a minimum thinking training, which is acquired with education [18].

Regarding the studied population's marital status, most were married and some in concubinage. It is important to consider family as an essential part of human care, because it is the family that will frequently share with the patient his fear, sadness, anxiety, suffering and happiness, generating more integration among them [19].

Several instruments have been proposed and used intending to assess the QL of patients with the most diverse illnesses. Choosing a certain instrument depends on the aim of its proposal, its practicality and the population to be studied.

The option to use SF-36 happened after verifying that most instruments that assess QL are developed in English, directed to populations that speaks that language [3] and that currently it is agreed that such means must not only be translated carefully, but also have their psychometric measurements tested in a specific cultural context [20]. It is an instrument with large acceptance, compact, easy to interpret, validated and applied in our country and in other languages, permitting comparison with other results. And there are authors who apply treatments that attempt to improve QL, acting as a bridge to definitive treatment [21].

Considering that refractory cardiac insufficiency is a chronic and progressive condition, the first result analyzed from the SF-36 questionnaire does not reveal totally unexpected. The population was requested to classify their current health according to a score defined as: "good", "bad" and "very bad". In the sample, eight (44.4%) patients classified their health as "bad" and three (16.7%) as "very bad", on the other hand, it was observed that seven (38.9%) surprisingly classified their health as "good" in this phase of the illness. These results (bad and very bad) are comparable to those found in the literature [17,22,23]; cardiovascular illnesses are those that most endanger patients' clinic condition, as well as their perception of health and QL. However, we did not find data that would justify the unexpected answer of seven (38.9%) patients who considered, despite all, their health as "good".

Comparing their current health status to that one year before, 5 (27.8%) patients classified their health as "much worse now", three (16.7%) as "a little worse now", three (16.7%) informed that their health "has not presented changes in one year", four (22.2%) stated "a little better now" and three (16.7%) "much better now" than one year before. In our opinion, it is highly criticizable the fact that the questionnaire does not consider the time of the illness; perhaps this fact could influence the analysis of the answers to the questionnaire. For example, a patient who has recently entered the transplant list could possibly not have the illness one year before. The survey did not assess the time the patient has been enrolled as a candidate for HT, followed correctly medication and the moment's clinical condition. The choice for HT is the last therapeutic alternative for the patient with refractory cardiac insufficiency, which imposes a much jeopardized clinical condition, with progressive worsening of his health status [1,3,17,23].

Physical weakness is an evident condition in this phase of refractory cardiac insufficiency, whereas the lack of energy is one of the patients' main complaints. [17] In our study of assessing physical performance capacity, 14 (77.8%) patients informed "being difficult to perform vigorous activities", three (16.7%) "being a little difficult" and one (5.6%) "not being difficult". When describing activities that demand physical vigor – picking up and carrying groceries, climbing several staircases, climbing one staircase, bending down, kneeling, walking more than 1 km, walking several blocks, walking one block, taking a shower or getting dressed – patients stated at least one or more activities in which it was difficult to perform.

In this way, physical compromising is common in other cardiovascular illnesses, however, by compensating the clinical status (medication optimization, clinical controls, physiotherapy, and psychological follow up), the patient feels disposed and active again, but in the initial assessment of the patient with refractory cardiac insufficiency, this condition is not present. In the functional capacity assessment, which analyzes the presence as well as the extension of limitations related to physical capacity, it was observed in the final score that the patients had a mean of 38% (remembering that less than 50% shows a compromised standard).

Regarding the occurrence of problems at work resulting from some emotional problem, "yes" was answered by 11 (61.1%) patients who said they "had done less tasks than they would like", 10 (55.6%) said they "had not worked or done any kind of activity with so much care as they generally did", 10 (55,6%) "had decreased the amount of time dedicated to work". When we observe the score obtained both regarding to the physical (13%) or the emotional aspect (33%), we notice that these results are compromised, what confirms the great loss of physical condition to develop heavy activities and the decrease of time that the patient dedicates to work or other activity. The work locates man in society and his environment, which reinforces Assis' statements that limitations imposed by the illness conduct the individual to labor incapacity, which makes him confront life's own fragility and vulnerability [24].

The score when assessing social aspects was 50%. When asked if the illness interfered in normal social activities, regarding family, neighbors, friends or in group, 10 (55.6%) patients answered that "there was no interference" or "slightly", or "moderately", eight (44.4%) said there was "much interference" and "sometimes extreme". When asked to assess how much time their health or emotional problems interfered in their social activities, six (33.3%) patients said "all the time", two (11.1%) patients answered "most of the time", four (22.2%) patients answered "a small part of the time" and six (33.3%) said "no part of the time". Diagnosis of a chronic illness is always a factor of rupture, of losses and of intense psychological and social disorganization. Emotional reactions that accompany facing the process of becoming ill result from the combination of several factors (individual history, personality dynamics, and autonomy of the individual in the affective, financial and social areas). Besides this, such reactions result from family dynamics. Psychic and social disorganization, imply on the structural disturbance of the patient's identity, as well as his familiar identity [25].

Assessing the mental health aspect, the score was 56%. This result makes believe that there is no significant change regarding mental health, which is good in this period waiting for the organ, and it will help postoperative recovery. When the illness phenomenon "interrupts" the individual's life, it generates psychic consequences. Being ill can mean fragility and dependence. Every illness makes patients vulnerable to some categories of psychological stress; those more frequent can be synthesized in: perception of self-integrity and the relation with self-esteem, separation anxiety and fears regarding loss and pain [25].

Despite having created different protocols to analyze QL, this subject continues to be a difficult assessment entity, although we have a subjective impression, it is difficult to measure QL and there is no uniformity regarding the assessment instruments in the several health institutions.

CONCLUSIONS

SF–36 is an applicable instrument, generating data to be compared with other populational groups, cardiopathy patients or patients with other illnesses. QL of patients with refractory cardiac insufficiency is considered "very bad". These patients' "vitality" and "functional capacity" are the most committed dimensions in this phase of the illness. These patients' "social" and "mental" aspects are the less affected.

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