

# The patient's perspective on value delivery in heart transplantation: case study at a university hospital.

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## Introduction

Ischemic heart diseases are the leading cause of death in Brazil, accounting for 24% of premature deaths in the country (IHME, 2017). With the rising prevalence of heart failure in its acute state, heart transplantation is considered a safe therapy and increasingly indicated (CCDIC, 2018).

Brazil has the largest public transplant system in the world, the SUS, and is the second country in absolute number of transplants. Despite the increase in the number of heart transplants (HT) in the country over the last 20 years, only 1/5 of the need is met (ABTO, 2018).

Research of value-based health in HT is still almost non-existent. The bibliographic research in 7 databases (BVS, EBSCO, PROQUEST, PUBMED, Science Direct, Scopus, Web of Science) returned

46 articles published from 2008 to 2020 related to quality metrics in heart transplantation, however, only 3 articles addressed the principles of value measurement promoted by Porter and Teisberg.

The purpose of this study was to describe and analyze perception of patients who underwent a heart transplant regarding their health-related quality of life, considering that the assessment of functional status and well-being after a health intervention can be considered an outcome measure.

## Methods

Brett et al (2018) carried out a systematic literature review where 317 quality metrics in solid organ transplants were identified and characterized. 23 metrics were used in studies related to HT and only 2 were PROMs, used in pediatric studies.

Based on the bibliographic research, 14 articles were revised to identify instruments most frequently used to assess health related quality of life in heart transplanted patients, resulting in 4 instruments more commonly used, which were selected for this study (SF-36, symptoms checklist, SEE, depression scale).

## Instruments

Organ Transplant Symptom and Well-Being Instrument	SEE – Self-efficacy for exercise scale	Brazilian Version of the Short Form Health Survey – SF-36
PH-Q2 Patient Health Questionnaire-2	Assessment of adherence to treatment	

## Summarized results

### Cohort

15 patients

- 8 Female
- 7 Male

50 years

average age of participants when they underwent heart transplantation

MAX 75 years

MIN 21 years

14 white

Only 1 patient self-declared brown

4 years since HT

Mean time from the HT to the date of the study

### Etiology of the HF

- Familiar: 6
- Non-Ischemic: 6
- Endomyocardial fibrosis : 1
- Ischemic: 1
- Sarcoidosis : 1

3 patients with comorbidities

2 diabetes melitus with no use of insulin and 1 with previous tabagism

40% Incomplete elementary school

- Complete elementary school: 7%
- Incomplete high school: 13%
- Complete high school: 27%
- Complete undergraduate school: 13%

More than half of patients reported at least 11 symptoms

+ Symptoms with more than 53% occurrence

- I wake up during the night
- I worry about my financial health due to my health status
- I feel lazy and apathetic
- I feel irritated
- I have difficulties falling asleep
- I have difficulties remembering
- I sleep badly
- I find it hard to concentrate
- I have a bigger appetite for food
- My libido/desire to have sex has decreased
- I feel angry

Unreported symptoms

+ 5 symptoms with 0% occurrence

- Due to my physical condition, I cannot shower.
- Due to my physical condition, I cannot dress myself
- Due to my physical condition, I cannot buy food for myself
- There's a burning pain in my hands
- I feel a throbbing pain and twinges in my hands

+ 11 Symptoms with 0% discomfort

Top 10 most stressful symptoms for patients

- I worry about my financial health due to my health status (47%)
- I wake up at night (33%)
- I have trouble falling asleep (27%)
- I sleep poorly (27%)I find it hard to concentrate (27%)
- I have a greater appetite for food (27%)
- My libido/want to have sex has decreased (27%)
- My legs are hurting (27%)
- I have no energy (27%)
- I feel lazy and apathetic (20%)
- I have trouble remembering (20%)
- I feel sad (20%)
- My muscles are hurting (20%)

Adherence to treatment

Adherence to treatment reported by patients averaged 73%, with the highest levels of adherence being observed in questions related to **drug treatment, attendance at medical appointments, and smoking cessation.**

The questions with the lowest scores were **following the nutritional recommendations, followed by the practice of the indicated physical exercise routine.**

No trends were identified in the lower scores related to gender or age of the respondent patients.

Self-efficacy for exercise

The average score of willingness to perform physical exercise among the participants was 49 out of 90.

The highest confidence level was related to **the possibility of performing physical exercise alone** and the lowest was related to **the possibility of exercising if you felt tired.**

Propensity to depressive disorder

Only 1 patient interviewed scored a score of 3 (7%), no patient scored a score higher than 3 and all the others (14, 93%) scored between 0 and 2.

Participant P10, the only one to score 3 in this instrument, is a female and was, at the time of the study, 26 years old.

General Quality of Life Assessment - SF-36

Dimension	Cohort of this study	Normative Data Brazil (45 – 54 years)	HT Taiwan	HT Germany – 6 weeks	HT Germany – 6 months
		Laguardia et al (2013)	Tung et al (2011)	Kugler et al (2011)	Kugler et al (2011)
Functional Capacity	77,00	76,50	41,25	75,00	80,00
Limitations due to physical aspects	61,67	78,80	44,45	75,10	87,50
Pain	73,80	75,50	48,71	89,60	84,00
General health	65,93	69,30	44,77	76,00	76,00
Vitality	67,33	71,70	47,23	65,00	70,00
Social aspects	72,50	84,00	48,10	70,00	87,50
Limitations due to emotional aspects	57,78	82,20	48,70	98,80	98,80
Mental Health	75,73	74,10	47,78	62,00	62,00
Self-perception of health	2,00				

## Detailed results

Patient	Age	Gender	Years since HT	PHQ2	SEE	Adherence to treatment	ite										OTSWI	
							FC	LPA	P	GHS	V	AS	LEA	MH	Self-perception of Health	Count of symptoms (quite a bit or very much)	Total count of related symptoms	
P2	42	F	5	None or minimum	80	High	95	100	100	80	95	100	100	100	++ Very Positive	0	0	
P5	54	F	5	None or minimum	32	Low	65	100	22	82	60	75	100	72	+ Positive	17	29	
P7	53	M	4	None or minimum	57	High	85	75	100	85	50	75	0	48	+ Positive	3	9	
P8	52	F	4	None or minimum	62	High	95	75	62	82	75	63	100	76	++ Very Positive	0	6	
P10	26	F	4	Probable	20	Medium	70	75	51	62	25	75	0	44	- Negative	8	20	
P11	43	F	4	None or minimum	28	Medium	70	50	51	57	20	13	0	44	0 Neutral	17	21	
P12	25	M	4	None or minimum	69	Medium	95	75	84	62	85	38	100	84	++ Very Positive	2	15	
P14	67	M	4	None or minimum	37	High	90	100	100	77	90	100	100	84	0 Neutral	1	13	
P15	62	F	4	None or minimum	47	Medium	80	0	100	62	80	38	100	100	++ Very Positive	0	5	
P17	55	F	4	None or minimum	80	Low	25	25	62	57	80	75	0	76	0 Neutral	6	20	
P19	59	F	4	None or minimum	38	High	85	50	72	62	60	100	67	76	0 Neutral	2	13	
P20	65	M	4	None or minimum	53	High	65	75	100	42	65	100	100	84	++ Very Positive	2	10	
P23	72	M	3	None or minimum	35	High	90	25	41	52	75	88	0	76	++ Very Positive	2	12	
P26	78	M	3	None or minimum	62	High	60	0	62	60	60	50	0	80	+ Positive	4	13	
P27	49	M	3	None or minimum	30	Low	85	100	100	67	90	100	100	92	+ Positive	10	18	

## Conclusion

Among the 15 studied patients, only 1 indicated that his general health status had deteriorated compared to the previous year (question 2 of the SF-36 instrument, P10) while 4 patients indicated that their health continued the same after one year, with no improvement or worsening. The average number of symptoms causing quite a bit or a lot of discomfort in these 5 patients was 7 symptoms, 2 symptoms more than the average of the studied group. If these patients were to be removed from the total average of symptoms of the studied group, the result would decrease to an average of 3 symptoms causing quite a bit or a lot of discomfort.

Monitoring the reporting of symptoms over time could act as a predictor of the deterioration of the general health status perceived by the patients, since, in this sample, it was possible to identify that patients who reported a worsening or stagnation in their health status also reported a greater burden of symptoms.

When analyzing the 5 patients with most reported symptoms causing quite a bit or a lot of discomfort, 2 indicated a general perception of positive health status compared to the previous year, while 2 indicated neutrality and 1 indicated worsening. Apart from one patient, all others scored at least one low score (less

than 30) in some domain of the SF-36 instrument. Among the 5 studied patients, 2 underwent reinterventions after transplantation, 4 had complications, 2 of them with a hospital stay of more than 10 days. In the questionnaire for adherence to therapeutic recommendations, 3 patients reported low adherence to the plan and 2 indicated a median one.

Based on this information, the health team responsible for clinical and psychological follow-up could discuss an action plan to improve the health outcomes reported by these patients and, once implemented, re-apply the instruments periodically in order to assess the outcome of the interventions and monitor quality of life. Jalowiec et al (2006) indicated that the main factor associated with lower patient satisfaction after HT would be the frequency and level of discomfort of symptoms. Such constant monitoring would be critical to increasing patient satisfaction and perceived value after HT.