ORIGINAL ARTICLE

Coping strategies after heart transplantation: psychological implications

Estratégias de enfrentamento pós-transplante cardíaco: implicações psicológicas

Paula Moraes Pfeifer[1], Patricia Pereira Ruschel[2], Solange Bordignon[3]

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Abstract

Objectives: **To investigate coping strategies used by patients submitted to heart transplantation and whether they are related to the perception of the disease and transplantation.**

Methods: **Cross-sectional study with quantitative and qualitative analysis. The sample of 32 patients was assessed by the Ways of Coping Scale and socio-demographic questionnaire, and five of them were selected for interviews. The internal consistency of the scale was assessed, the variables and strategies involved were crossed and content analysis of interviews, investigating the existence of a relationship with the speech of the participants.**

Results: **The individuals have used all coping styles, with a predominance of the problem-focused strategy. Psychologically prepared patients showed a statistically significant increase in the use of problem-focused coping and seek for social support. However, a significant increase in the use of emotion-focused coping was observed in patients who were not prepared. Analysis through the method of Bardin showed as categories: disease; reaction to call; transplantation; fantasies; postoperative; team and coping.**

Conclusion: **Patients with a transplanted heart make use of all coping strategies, with a predominance of the problem-focused strategy. Psychologically prepared individuals used more active coping strategies, which highlights the importance of psychological support during the process.**

Descriptors: Heart transplantation. Adaptation, psychological. Sickness impact profile.

Resumo

Objetivos: **Verificar as estratégias de enfrentamento utilizadas por indivíduos que tiveram o coração transplantado e suas relações com percepção da doença e do transplante.**

Métodos: **Estudo transversal com análise quantitativa e qualitativa. A amostra de 32 pacientes foi avaliada pela Escala Modos de Enfretamento de Problemas e questionário sociodemográfico; e cinco deles foram sorteados para entrevista. Realizou-se a avaliação da consistência interna da escala, cruzamentos entre as variáveis e os estilos de enfrentamento e a análise de conteúdo das entrevistas, relacionando os resultados ao discurso dos participantes.**

Resultados: **Os indivíduos utilizaram todos os estilos de enfrentamento, predominando o focalizado no problema. Nos participantes que receberam preparo psicológico, houve aumento estatisticamente significativo dos enfrentamentos focalizados no problema e na busca de suporte social. Entretanto, naqueles que não receberam preparo, houve aumento significativo da utilização do enfrentamento focalizado na emoção. Através do método de Bardin, revelaram-se como categorias: doença, reação ao chamado, transplante, fantasias, pós-operatório, equipe e enfrentamento.**

Conclusões: **Os participantes utilizaram todos os estilos de enfrentamento, predominando a estratégia focalizada no problema. Os que receberam preparo psicológico usaram maior número de estratégias de enfrentamento ativas, o que evidencia a importância do acompanhamento psicológico durante o processo.**

Descritores: **Transplante cardíaco. Adaptação psicológica. Perfil de impacto da doença.**

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1. Psychologist intern at Instituto de Cardiologia; Specialized in Hospital Psychology, Porto Alegre, RS, Brazil.
2. Psychologist Coordinator of the Psychology Service in Instituto de Cardiologia – Fundação Universitária de Cardiologia/ IC-FUC; Coordinator and Preceptor of Integrated Internship in Health: Cardiology – RISC, Porto Alegre, RS, Brazil.
3. Cardiologist at Instituto de Cardiologia - Fundação Universitária de Cardiologia/ IC-FUC, Porto Alegre, RS, Brazil.

Work carried out at Instituto de Cardiologia, Fundação Universitária de Cardiologia/ IC-FUC, Porto Alegre, RS, Brazil.

Correspondence address:
Paula Pfeifer
Instituto de Cardiologia – Serviço de Psicologia
Av. Princesa Isabel, 395 – Porto Alegre, RS, Brazil – Zip code: 90620-001.
E-mail: paulabmpfeifer@gmail.com

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Abbreviations, Acronyms & Symbols	
HT	Heart transplantation
WOCS	Ways of Coping Scale

INTRODUCTION

Heart transplantation (HT) can be seen as a process, since it does not imply a "cure", according to the popular conception of absence of disease. HT can significantly improve the quality of life, but the patient will have to adapt to multiple limitations and other health problems [1,2].

A heart transplant requires lifestyle changes, so that the individual may cope with the demanding postoperative protocol and side effects of the drugs used [3-5]. The patient is also confronted with feelings that are roused by the constant threat of rejection, uncertainty of long-term prognosis, ambivalent psychological acceptance of the transplanted organ and influence of the cultural symbolism of the heart [3-5].

These particularities can raise the levels of anxiety and stress and trigger depression, which is considered a relevant risk factor for mortality after HT [3,6,7]. The depressive reaction can influence the clinical picture and compromise good results during the rehabilitation phase, since it may combine with anxiety and directly affect treatment adherence [4].

It is thus of fundamental importance that the patient is able to psychologically defend himself, using a range of coping strategies. These strategies include a hierarchy of flexible, purpose-oriented defense mechanisms, ranging from less adaptive to more evolved types of defense. They are defined as a stress response, which may be behavioral or cognitive, with the purpose of decreasing the aversive characteristics [8].

These strategies can be primarily focused on the problem, by modifying the relationship between the person and the environment, or on emotion, adapting the emotional response to the problem. They represent situational responses, influenced by the perception of environmental and personal systems and by the events of life. Evasive, emotive, fatalistic coping strategies are associated with a smaller capacity of personal control over the disease, increasing levels of depression and anxiety and decrease in treatment adherence [8-10].

The present study aims at the investigation of coping strategies used by patients who have had a HT and at analyzing if there is a relationship between the adoption of these strategies and the perception of the disease and transplantation.

METHODS

In this cross-sectional study with quantitative and qualitative analysis, sample size was calculated based on the study by Seidl et al. [11]. Thirty-two patients attended at the Transplantation Service of Instituto de Cardiologia do Rio Grande do Sul (Porto Alegre, RS, Brazil), of both genders, aged over 18 years, and submitted to HT at least one month previously, were included.

The instruments used in this study included a demographic questionnaire, with basic data of the patient and information concerning the disease, transplantation and quality of life; a semi-structured-interview with thematic analysis for collecting information about the participant's perception in relation to disease and transplantation; the medical record for obtaining complementary data; and the Ways of Coping Scale (WOCS). The WOCS is a Likert type scale which assesses the magnitude of coping strategies used by the individual when confronted by stressors. The scale is composed of 45 items, with answers ranging from 1 (I never do that) to 5 (I do it always), and was adapted for use in Brazil by Gimenes & Queiroz [8,11,12].

This study was approved by the institutional Ethics Committee Research, is in accordance with the Declaration of Helsinki, and follows the Resolution 196, of October 10, 1996 [13].

Patients returning to the health center for consultation were informed about the study and invited to participate. Those who agreed to participate signed an informed consent and answered to a demographic questionnaire and the WOCS. Five of the patients were randomly selected for interviews, which were recorded with the permission of the participants.

The data were tabulated and the interviews were fully transcribed. The results were analyzed in two steps. First, the internal consistency of the WOCS factors was assessed using the Cronbach's alpha coefficient, with the statistical software SPSS version 17.0. Categorical variables were described by absolute and relative frequency, and quantitative variables, through the mean and standard deviation or median and interquartile range. Since coping is a situational concept, the variables and strategies involved were crossed. A difference was observed between participants who received or not psychological preparation for HT, and between those with or without psychiatric disorders. The participants were then assigned to groups according to the presence or absence of the analyzed variables, and the coping strategies were compared through Student's t-test for independent samples. *P* values lower than 0.05 were considered statistically significant. The variables were evaluated through the Pearson and Spearman correlation.

The second step addressed the qualitative analysis of interviews, through the content analysis method described by Bardin [14]. The contents of interviews were separated into units of registry, i.e. phrases with specific themes, which reflect an individual perspective. Subsequently, they were grouped into categories and subcategories according to the recurring content in the speech of the participants, in order to articulate a group perspective [14]. The results of the two analyses were compared, for determination of the types of coping strategies used and relating the data obtained to the speech of individuals.

RESULTS

Descriptive results

The main demographic and clinical characteristics of the sample are presented in Table 1. Data that indicate quality of life show that 93.8% of the participants have some type of leisure activity and 43.8% live with spouses and children. In relation to sleep, 81.3% of the patients sleep on average 5 to 8 hours per night; 87.5% report having dreams, and for 31.3% of them, dream contents reported are related to death.

Evaluation of internal consistency

WOCS reliability to assess coping strategies was acceptable. The results of the Cronbach alpha analysis of factors was: coping focused on the problem = 0.885; coping focused on emotion = 0.671; coping through religious/fantastic practices = 0.652; and coping aimed at seeking social support = 0.361.

Coping strategies

Participants used all types of coping strategies, with predominant focus on solving the problem. The coping strategies presented the following averages and standard deviations: (a) focused on the problem 3.78±0.77; (b) focused on emotion 0.54±2.11; (c) coping through religious/fantastic practices 0.86 ± 3.34; and (d) aimed at seeking social support 3.22±0.75.

The analysis of variables age, time of HT and schooling showed that only the variable schooling presented a moderate inverse correlation with the coping strategy adopted (rs = - 0.471; $P = 0.006$). When the relationship of coping strategies among themselves was investigated, a moderate direct correlation was observed between coping focused on the problem and the search for social support (r = 0.450; $P = 0.010$).

Table 1. Characterization of the sample (n=32)

Age	58.5 (23-71)
Sex-male	23 (71.9)
Marital status-steady relationship	27 (84.4)
Education – incomplete elementary school	14 (43.8)
Professional status-inactive	19 (59.4)
Cardiomyopathy-dilated	25 (78.1)
Etiology-ischemic	16 (50)
Transplant time*	105.5 (2-211)
Psychological assessment	25 (78.1)
Psychological preparation	21 (65.6)
Duration of psychological follow-up	37 (0-243)
Presence of psychiatric disorder	9 (28.1)
Diagnosis of major depression	7 (21.9)
Presence of suicidal ideation	4 (12.5)

*Data are presented in n(%); median and interquartile range. *Variables presented in months*

The comparison of coping strategies used between groups of participants who had or not received psychological preparation for HT is presented in Figure 1. The comparison of the strategies among the groups of patients with or without psychiatric disorders is presented in Figure 2.

Bardin's content analysis

The qualitative analysis of the content of the interviews can be seen in Chart 1.

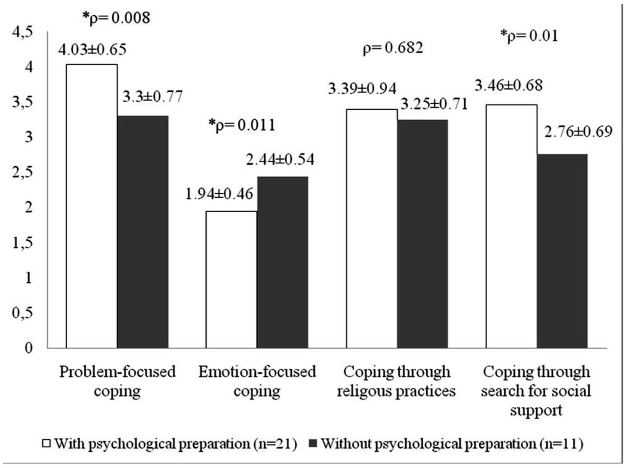

*Fig. 1 – Comparison of coping strategies among patients receiving or not psychological preparation for hearth transplantation (μ±SD). *P<0.05 significant*

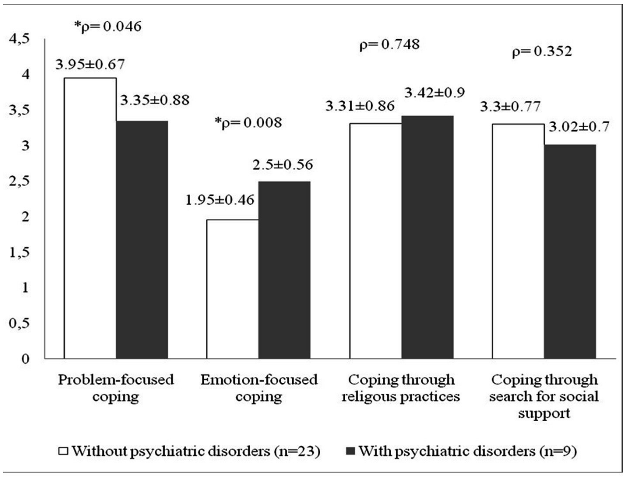

*Fig. 2 – Comparison of coping strategies among patients with or without psychiatric disorders (μ±SD). *P<0.05 significant*

Chart 1. Analysis of the contents of patients' speeches.

Categories	Subcategories	Verbalizations
Disease	Invisibility Disabling symptoms Irreversibility	Who met me on the street though that I had nothing. So I couldn't walk well, or work. It was irreversible by the time it was decided for a transplantation.
Reaction to calls	Ambivalence Decision Coping	It is hard. One keeps thinking: Well, will I come back or not? There was the fear, then after that I started having that feeling that it was going to be all right. Then I must be decided and know that I'm leaving and I don't know if I'll come back. I was determined: take it or leave it. If I do not live I'll die. I'll try to live. The other time, they called me and I didn't got to come. Then when they called me last time, I did.
Transplantation	Solution Opportunity Happiness Gratitude Ambivalence Fear	Then the doctor suggested entering a queue for transplants. When the transplantation was decided, there was no other solution. I was taking five medications and did not improve, had no perspective on life. I was disillusioned, and when I saw this light at the end of the tunnel I felt a great joy. A joy, a hapiness. How good it is to be alive. I thank you, because if I hadn't done it I would be no longer here. Sometimes, I would rather not have done. The fear that it does not work well. I have this concern that it can return.
Fantasies	Change of feelings Death of another Fate of the organ	The wife of a future colleague cried and I asked why, and she replied: Because now, that he have a new heart, I keep thinking that he won't love me as much he did. I thought that someone had to die for me to live. One of my grandchildren asked what they had done with my heart that was taken away, and my wife said: they must have thrown it in the trash.
Post-surgery	Fear of pain Happiness Suffering Recovery of autonomy Threat of rejection Adherence	I imagined a terrible pain after the surgery. I did not die. I'm alive. The feeling when I woke up was very good. I went through a lot, after I did the transplant, I heard voices. On the third day I got up, in the room I showered alone. I have take care of many things which need consideration, because if I stop taking cyclosporine or some other medication needed to avoid rejection, it is certain that I will die. The medication I do self medicate, because I already have separate everything, everything is already set.
Team	Receiving Trust Psychologist	When I was admitted to the hospital, I was treated with great affection. This helped me a lot. When I came to have the transplant, everyone around me was worried. One day I will die. Now, if I'm get in, they will do everything to save my life. I had great faith, was sure that the doctors were going have success with my surgery. At that time, only a doctor worked, there was no follow-up with you as it is now. I changed my mind talking to a psychologist. She explained things to me, telling about what was going to happen, saying that I was not going to kill anyone.
What helped to accept heart transplantation?	Will to live End the suffering Psychological preparation Personal characteristics	The will to live, for sure. I had to stop in the street because they had no more strength, it was bad. So this is what pushed me to go to fight. The psychologist helped a lot, because the first time I was called I didn't come. My way of seeing things. I do first to think later.

DISCUSSION

Several studies have examined coping strategies in the context of health. However, very few of them have investigated coping strategies used in the period after a HT, with virtually no research combining quantitative and qualitative designs [15].

Findings of the present study are consistent with previous reports. Early-stage heart disease is not always accompanied by symptoms, approaching the patient silently [5]. Unlike other diseases, such as certain types of cancer that modify the appearance of the individual, it is invisible, as can be inferred from the participant's speech: *People who met me on the street thought that I was well.* This aspect, coupled with emotional difficulties in dealing with the disease, may influence the delay in looking for treatment and poor adherence to treatment.

The evolution of the disease leads to the development of heart failure and crippling symptoms [1]: *So I couldn't walk well, or work*. Thus, the indication for HT represents the possibility of survival and improvement in the quality of life [2,16]: *I was disillusioned, and when I saw this light at the end of the tunnel I felt a great joy. I was taking five medications and did not improve, had no perspective on life*. At the same time, it arouses intense anxiety and fantasies: *I thought that someone had to die for me to live*. There is also a peculiarity in the influence of cultural symbolism of the heart, associated with life and emotions: *The wife of a future colleague cried and I asked why, and she replied: Because now, that he have a new heart, I keep thinking that he won't love me as much he did*. In addition to the physical suffering imposed by the disease, the patient is exposed to emotional distress by the uncertainty of survival and confrontation with death. Therefore, the reaction involves ambivalent feelings [3]: *It is hard. One keeps thinking: Well, will I come back or not?*

HT requires from the patient a series of adaptive tasks [3]: *I have take care of many things which need consideration, because if I stop taking cyclosporine or some other medication needed to avoid rejection, it is certain that I will die*. These events may generate high physical and psychosocial impact, because the transplant is seen as a new disease and not a cure: *Sometimes, I think I would rather not have gone through this*.

In the immediate postoperative period, the participants relate a feeling of happiness for having survived: *I did not die. I'm alive. The feeling when I woke up was very good*. At the same time, it is a highly disorganizing experience: *I went through a lot, after I had the transplant I heard voices*.

As in other studies, most of the survivors of a HT were male and were in a stable relationship, which indicates greater social support and is considered a protective factor [15-17]. A high rate of professional inactivity was observed among the participants, which can be associated with the high emotional impact of the transplantation [18]. A high prevalence of ischemic dilated cardiomyopathy was also observed [19].

Considering the psychical elaboration of the HT, most participants remembered dream, which is an important indicator of emotional capacity. It is important to observe that most dreams were related to death, highlighting again the high emotional impact of transplantation and the attempt of elaboration of the traumatic experience.

The WOCS evaluates four types of coping strategies: coping focused on the problem, on emotion, in religious/ fantastic practice and in the search of social support. In the present study, the scale showed acceptable reliability to evaluate such strategies.

In general, participants made use of all types of coping strategies, with a predominance of the strategy focused on solving the problem and, to a lesser extent, on emotion. The problem-focused strategies correspond to a cognitively active way of dealing with the situation, through behaviors of approaching the stressor in order to solve the problem. They are also related to positive thinking, i.e. a positive perception of the situation: *I was determined: take it or leave it. If I do not live I'll die. I'll try to live*. Strategies focused on emotion are a passive way of dealing with the situation, through the adoption of evasive and escape behavior in relation to treatment. They are related to negative emotional reactions and fantasy thoughts of self-guilt and or blaming other people [11,15]: *The other time, they called me and I didn't got to come. Then when they called me the last time I did it*.

Since coping strategy is a situational concept, and as such influenced by the individual’s internal and external environment, it was necessary to crossover and investigate correlations between variables and coping strategies. In this sample, no correlation was observed between the variables age and coping strategies [11], or between time of HT and coping strategies [15]. Therefore, the variables age and time of transplant did not influence the choice of coping strategy used by the patients. However, the variable schooling correlated inversely with coping by adoption of religious practices [11]. The coping strategy which uses the adoption of religious practices is related to a range of feelings, from hope and faith (pertinent to the situation) to fantastic thinking, which can justify passive avoidance behaviors and the hope for a miracle (making treatment adherence more difficult).

According to the literature, factors that may be responsible for poor treatment adherence include inadequate knowledge of the process, depression, anxiety, low social support, substance abuse, stress, persistence of psychological suffering, difficulty of access to medication and poor relationship with the team [8]. Therefore, a good relationship with the team can be fundamental [20]: *When I was admitted to the hospital, I was treated with great affection. This helped me a lot. I had great faith, was sure that the doctors were going have success with my surgery. I changed my mind talking to a psychologist. She explained things to me, telling about what was going to happen, saying that I was not going to kill anyone*.

In addition, the use of coping strategies focused on the problem and in seeking social support presented direct correlation, i.e. the increase in coping with the problem is accompanied by greater search for support. The search for social support is related to the demand for instrumental and emotional support or information to assist in coping with the situation [11]. Thus, both strategies involve the adoption of an active posture of the patient in relation to treatment, thus favoring adherence, since they influence both the feelings of confidence in the health team, as the adoption of behaviors of search for health aid.

Participants who had received psychological preparation used with higher frequency coping strategies focused on problem (*P*=0.008) and on the search of social support (*P*=0.01) than those without this preparation. In addition, there was a decrease in the use of emotion-focused coping (*P*=0.011). The differences were statistically significant. Taking into consideration that most of the participants had ischemic dilated cardiomyopathy before the HT and that the literature suggests that coronary patients have type "A" personality, these data show the relevance of psychological preparation. Individuals with type "A" personality are described as competitive, rigid, self-controlled, committed to the work and, often, unable to rest. They are described as persons who try to show independence, have difficulty in relating with others and in taking a passive and dependent stance. In addition, they have difficulty in identifying and dealing with their feelings, which makes them more fragile when sick [21].

According to these characteristics, individuals who are not well prepared for the transplant would use more frequently the emotion-focused coping strategy, due to their emotional difficulties. Because of their difficulty in relating with other persons and assuming a dependent role, they would use less frequently a coping strategy that relies on seeking social support. Similar results were observed for patients who did not receive psychological preparation. These behaviors deserve attention, since they can hinder treatment adherence as well as indicate a greater vulnerability of the patient [6,15].

Therefore, the data obtained from the group of patients psychologically prepared for the HT shows the relevance of this intervention. This preparation allows the patient a moment to talk about the transplant, so that he becomes aware of his fantasies and feelings, as well as the personal way of addressing the situation, a fact that enables a change of behavior and favors the adoption of coping modes more active and adapted to the situation, such as the confrontation focused on solving the problem and the search for social support [22]. These coping strategies are fundamental to the survival, since they influence the behavior of adherence to treatment [9,15]. In addition, the psychological treatment relieves feelings of stress, anxiety and depression, facilitating the process [15].

A comparison of strategies among patients with and without the presence of psychiatric disorder found that in seconds there is a predominance of problem-focused coping style (*P*=0.046) and less frequently the emotion-focused strategy (*P*=0.08). However, patients with psychiatric disorders showed a non-significantly higher frequency of coping by religious practice (*P*=0.748), and a significant increase in the use of emotion-focused coping (*P*=0.352). These results suggest greater use of passive strategies, indicating an inability to deal with the post-transplant period, as pointed by other studies that emphasize the role of major depression as a risk factor in the post-transplantation period [6,7,15,23].

Taking into account these particularities, the role of the psychologist must start in the preoperative period and extend during the post-transplant period, according to the needs of each patient. In the pre-transplant period, the psychologist assesses how the patient processes information about his health, how he receives the indication for transplantation and what is his level of knowledge of the process. Therefore, the use of psychoprophylaxis – a technique developed by psychoanalyst Arminda Aberastury – emphasizes the importance of working the anxieties and fantasies related to the surgery. Therefore, it is necessary to explain every detail of the surgery, from the anesthesia to possible indispositions, decreasing in this way the postoperative anxiety and trauma by making it possible to elaborate fantasies, suffering and feelings of unsafety associated with transplantation, as well as the incorporation of a new body image [24].

In the period subsequent to the HT, psychological aspects related to the feeling of loss of the heart, acceptance of the new body and adaptation to changes in life habits should be addressed. In addition, the patient's sense of autonomy, self-efficacy and responsibility for his own health care, as well as the stimulus to return to life activities, should be strengthened in order to increase adherence to the treatment [9,18,25].

One of the possible limitations of the present study is that the results cannot be generalized to the overall population, since the sample is small, despite being representative of the institutional reality – more than 55% of patients undergoing living transplantation – and reflecting clinical data already observed. In addition, the WOCS showed poor reliability in the analysis of coping strategy focused on seeking social support, highlighting the importance of further studies with more representative samples, with patients with psychiatric disorders and the need for a review of items that represent this factor in WOCS.

CONCLUSION

Individuals who underwent HT make use of all coping strategies, with a predominance of strategies focused on the problem. The use of this active coping strategy implies behaviors more adapted to the process and responsible for greater adherence to treatment. Participants who were psychologically prepared for HT used a greater number of active coping strategies, a fact that highlights the importance of psychological support during the process. These results indicate the relevance of further studies to investigate the influence of preparation in relation to coping strategies adopted in larger samples.

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