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Heart transplantation: the experience of patients with Chagas disease

TRANSPLANTE CARDÍACO (TC): A EXPERIÊNCIA DO PORTADOR DA DOENÇA DE CHAGAS

TRASPLANTE CARDÍACO (TC): LA EXPERIENCIA DEL PORTADOR DE LA ENFERMEDAD DE CHAGAS

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ABSTRACT

Successful heart transplantation in patients with Chagas disease depends on special care to be provided during all phases of the transplantation process, and requires specific and rigorous follow-up by the health care team. Recipients must be aware of the permanence of the trypanosome in their organisms as well as of the possibility of infection reactivation after transplantation. Therefore, the patient's knowledge regarding this condition and his active participation in his own treatment are of utmost importance. This study aimed at investigating heart transplantation as experienced by patients with Chagas disease, seeking to understand the meanings that they attribute to such an experience. The methodological procedures included: patient selection; interviews; data analysis, indication of the meaning units and individual analysis; search for discourse convergence; and hermeneutic analysis of convergences. From the data analysis, the following themes emerged: the time lived by recipients with Chagas Disease; the conception of heart transplantation presented by patients with Chagas Disease; and care in the course of heart transplantation.

KEY WORDS

Heart transplantation.
Chagas disease.
Nursing care.
Qualitative research.

RESUMO

O sucesso do transplante cardíaco com portadores da doença de Chagas está condicionado a cuidados especiais durante todas as fases do transplante, com necessidade de acompanhamento específico e rigoroso pela equipe de saúde. Os receptores devem estar conscientes da permanência do Trypanosoma no organismo, e das possibilidades de reativação da infecção após o transplante. Portanto, seu conhecimento dessa condição, e a sua participação ativa no próprio tratamento, têm importância fundamental. O objetivo do estudo foi investigar a experiência do transplante cardíaco vivenciada por pacientes portadores da doença de Chagas, para buscar compreender os significados que eles atribuem a esta experiência. Os procedimentos metodológicos abrangeram: a seleção dos pacientes; as entrevistas; a análise dos dados, indicando as unidades de significado e a análise individual; a busca de convergências dos discursos; e análise hermenêutica das convergências. Da análise dos dados emergiram os seguintes temas: o tempo vivido pelo receptor, portador da Doença de Chagas; a concepção do TC apresentada pelo portador de Chagas; o cuidado na trajetória do TC.

DESCRIPTORES

Transplante de coração.
Doença de Chagas.
Cuidados de enfermagem.
Pesquisa qualitativa.

RESUMEN

El éxito del trasplante cardíaco con portadores de la enfermedad de Chagas está condicionado a cuidados especiales durante todas las fases del trasplante, con necesidad de acompañamiento específico y riguroso por el equipo de salud. Los receptores deben estar conscientes de la permanencia del Tripanosoma en el organismo y de las posibilidades de reactivación de la infección después del trasplante. Por lo tanto, su conocimiento sobre esa condición y su participación activa en el propio tratamiento es de fundamental importancia. El objetivo del estudio fue investigar la experiencia del trasplante cardíaco experimentada por pacientes portadores de la enfermedad de Chagas, para comprender los significados que ellos atribuyen a esta experiencia. Los procedimientos metodológicos abarcaron: la selección de los pacientes; las entrevistas; el análisis de los datos, indicando las unidades de significado y el análisis individual; la búsqueda de convergencias de los discursos; el análisis hermenéutico de las convergencias. Del análisis de los datos emergieron los siguientes temas: el tiempo vivido por el receptor, portador de la Enfermedad de Chagas; la concepción del TC que tiene el portador de Chagas; el cuidado en la trayectoria del TC.

DESCRIPTORES

Trasplante de corazón.
Enfermedad de Chagas.
Atención de enfermería.
Investigación cualitativa.

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INTRODUCTION

Chagas disease is endemic in South America. It is caused by the protozoan *Trypanosoma cruzi*. Cardiac impairment, referred to as cardiomyopathy, is the major type of cardiac damage caused by the infection, due to its frequency and severity. In Brazil, heart transplantation (HT) is indicated as the first treatment option for the occurrence of heart failure in patients with the infection as a result of the success of this therapy in increasing the survival and quality of life of transplanted individuals⁽¹⁻³⁾.

At first, many international researchers refuted HT as an indication for patients with the infection because the immunosuppressants used after transplantation could reactivate the disease. However, following successful experiences in Brazil, most of the heart care centers in the country began to perform transplantation in infected patients⁽¹⁾. Studies have shown that, in those recipients, HT may present similar or, at times, better results than in heart failure caused by other pathologies⁽¹⁻³⁾. A successful procedure, however, is dependent on special care to be provided to the patient, who must have specialized post-operative care, and will require specific and rigorous follow-up for life.

Since it is exclusively a Brazilian experience, the literature on HT for patients with Chagas disease is restricted to national studies showing the results and benefits attained after HT in regards to overcoming the cardiomyopathy symptoms and the specific use of immunosuppressants to prevent Trypanosomal reactivation⁽¹⁻³⁾. Such studies suggest that successful HT means not only ensuring the survival of patients in the final phase of cardiomyopathy, but also enabling them to achieve satisfactory levels of physical capacity and quality of life. This makes educational programs a crucial part of recovery: recipients must be aware of the permanence of the trypanosome in their organs and the possibility of infection reactivation after HT. Therefore, the need for consistent professional follow-up after transplantation is noteworthy, as it will support and educate recipients so as to ensure their effective participation in treatment.

Studies on HT outcomes have shown that patients' low adherence to post-operative follow-up is related to greater risk of morbidity and mortality⁽⁴⁻⁶⁾. On the other hand, relationship difficulties between patients and the professionals on the health care team could also result in low treatment adherence⁽⁶⁾. The findings in these studies suggest that knowledge of the conflicts experienced by HT patients is crucial, as it will help them to accept the changes that have occurred as well as the strict rules of post-HT follow-up. Awareness of this reality is essential to maintain the benefits of HT, and it is the first step for patients to take in owning responsibility for their own treatment.

Patients' education to empower them to care for themselves involves a set of strategies to stimulate the development of their autonomy and encourage active participation in their own treatment

Some presuppositions condition patients' adherence to the health care team's care plan: their acknowledgment of the fact that they are responsible for their own care, rather than it being strictly the responsibility of the professionals; respect for their beliefs concerning health care; and acceptance of their self-determination in this process⁽⁷⁾. In this conception, patients' education to empower them to care for themselves involves a set of strategies to stimulate the development of their autonomy and encourage active participation in their own treatment; this denotes understanding that it is *only from listening to patients, their wishes and singular significations that we will be able to conjointly outline a care plan*⁽⁸⁾.

Considering the above, qualitative research regarding patients' perceptions about what happens in the transplantation process will provide important information to learn about their needs based on their own viewpoint.

The literature consulted provides no information concerning the subjective experience of transplantation for patients with Chagas disease. Even considering the originality and specificity of this study, results from international research on the quality of life achieved by patients without *Trypanosoma cruzi* after HT^(4-6, 9-13) will be used during data analysis for the purpose of presenting similarities and divergences from other published studies.

OBJECTIVE

This study aimed at investigating heart transplantation (HT) as experienced by patients with Chagas disease in order to understand the meanings that they attribute to such experience.

METHOD

In the present study, Existential Phenomenology was used as advocated by Merleau Ponty, who proposes a return to the same things in seeking the structure of the investigated phenomenon⁽¹⁴⁾. Phenomena are perceived according to lived experiences, which, when described without marks placed by theoretical concepts, expose the pre-reflective – the experience lived prior to reflection. The soil of the lived experience constitutes the very ground in which science plunges its roots, in the phenomenological conception⁽¹⁵⁾. When the participants were asked to describe their heart transplantation experiences, we understood that each person did so according to his own perception of the lived experience, which is individual and unique, contextualized in its way of existing in the world. Such various individuals' perceptions, at different times and places, are characteristic of the phenomenon, which may present divergences and convergences. In view of the convergences, or common

meanings to individual reports, the researcher articulates *invariants* of the phenomenon which are manifested in the reported experiences. That is, the *general truths* which describe the structure of the phenomenon: *the experience of having one's heart transplanted* as a result of being a Chagas disease patient.

The authors of the study are a nurse and faculty member of the Botucatu School of Medicine - UNESP who did not perform HT activities and, therefore, was not involved with the care being provided to the participants; a heart surgeon who was responsible for the surgery staff at INCOR and a faculty member of the University of São Paulo School of Medicine; and a philosopher and phenomenologist who was also a faculty member at Rio Claro School of Mathematics - UNESP.

The close relationship of the three members of the group of researchers made it possible for each one of them to take responsibility for different research activities. Hence, due to his experience in HT and vision of the phenomenon under study, the surgeon was in charge of presenting the universe of HT patients with Chagas disease to the other two researchers, thus introducing them to an understanding and approximation to this context, particularly as concerns the approach to possible participants. He also collaborated with his expert vision in the elaboration of the final results achieved in the study. The nurse, by providing continuity with previous studies on organ acquisition and transplantation, perceived the phenomenon and placed it under focus, approached the patients and selected those who would become participants in the study, and developed the analysis of the statements and advanced in the study together with the philosophy researcher. The latter fully defined the procedures in philosophical terms and, together with the nurse, performed the structural analysis, seeking for convergences of individual discourses, as well as performed the hermeneutic analysis of convergences.

Data collection

To start, possible participants were contacted according to the following criteria: being a Chagas disease patient and having undergone HT from 1994 to 2004. Nine males and females aged 20 to 60 years, and from different social and economic levels, were selected. The interviews were guided by one question: *How do you view the experience of having a transplanted heart?* The interviews lasted from 45 to 80 minutes.

As regards ethical procedures, the research project was previously approved by the Ethics Committee of INCOR (registration nº 2233/03/027). The patients were informed about the study and its objectives, about the freedom to participate or not, and that the care provided to them would not be affected if they refused to participate. Their right to anonymity and confidentiality concerning the content of the interview as well as the possibility of interrupting their par-

ticipation in the study at any time was ensured. The participants then signed a Free Consent form.

The interviews were tape-recorded, fully transcribed and interpreted based on the following procedures: reduction, phenomenological analysis and interpretation⁽¹⁴⁾, according to the following steps⁽¹⁶⁾:

a) The participants' descriptions were first analyzed and interpreted individually (*ideographic analysis*). After carefully and repeatedly reading the description, the meaning units, that is, the parts of the statements which answered the researchers' question, were identified. The meaning units were, one by one, analyzed and interpreted under the view of the studied phenomenon. Upon completion of the ideographic analysis, the researchers articulated their own understanding of each participant's description.

b) After the individual analysis of all statements, their convergences were sought (*nomothetic analysis*), which showed the confluence of the participants' perspectives concerning the lived experience, thus unveiling the general truths about the investigated phenomenon, or its *essence*.

DATA PRESENTATION AND ANALYSIS

The convergences of the meaning units in the discourses were grouped into three essential topics: *the time lived by recipients with Chagas Disease; the conception of HT presented by patients with Chagas Disease; care in the course of HT*.

In the analysis of each topic, we will mention the participants' statements in order to clarify data interpretation. At the end of each quotation, the number of the discourse to which it belongs will be indicated.

TOPIC: The time lived by recipients with Chagas disease

In this category, we will focus on the time lived by patients during their course as heart disease patients due to infection with *Trypanosoma cruzi*: from the moment when they became aware of their heart failure and subsequently underwent HT, to the post-HT period and the resulting changes. These convergences include the following topics: *how patients experienced finding out that they had Chagas disease; the time lived while waiting for the heart to be transplanted; the time lived after HT; and the time lived in the moment of taking possession of another person's organ*.

The recipients perceived falling ill with Chagas disease as momentous in their existence. When heart failure occurs, the most essential functions, such as breathing, eating, drinking and moving, become impossible.

Some reported that the discovery of the disease coincided with the onset of sudden heart failure symptoms. One participant described:

I started feeling breathless. Then I stopped smoking. I thought it was because of smoking. It became worse and

worse. I saw a cardiologist in Barueri. Then, we could see that my heart was enlarged. It was really large (P5).

The time lived by the patient above advanced in terms of changes: he was forced to break a habit that brought him pleasure in spite of being harmful, the habit of smoking. He perceives himself as being unsuccessful in the attempt to reduce the symptoms and decides to seek help from a professional. Abruptly, he finds out that he has a severe lesion in his heart.

To others, the development of the disease occurred gradually, in a long and drawn-out process of deterioration of cardiac function, until the organ's eventual failure. The time lived was marked by continuous alterations in both the perception of severity of symptoms and medical procedures. One participant said:

I spent years suffering with a pacemaker. Then the doctor told me that I needed transplantation (P4).

The pacemaker was an attempt to delay HT. She describes how she spent that time suffering.

Another recipient reports:

Well, I had been treated for over 10 years. Growing... To me, it was fast, you know, although it had been 10 years, it got worse. I started to feel scared (P9).

He experiences time by perceiving himself becoming worse quickly. This scares him. He is aware that he is in danger of dying.

The time lived is marked by pain, restrictions and tiredness:

Pain; I couldn't walk much; it was tiring... and about things at home: eating saltless food, drinking small amounts of liquids. Everything was controlled, and I couldn't take it. When they began to perform the tests, I had the pacemaker put in, and so on. It didn't help. They referred me to the transplantation team; they changed the medication. I still felt bad, very tired, breathless (P8).

They spend their time going to and coming from hospitals. There are periods of hospitalization. Medications keep them alive. Suffering is not attenuated; it is living in agony:

I was scared to talk to people in the past because of the tiredness that I felt. Whenever I picked up a magazine to read it would make me hate myself... it made me feel even angrier with myself. Tired; that agony; I couldn't drink a sip of water. Whenever I ate, I felt such terrible pain that I groaned all night (P6).

In the temporality existentially lived, the recipients perceived themselves as being in a struggle for maintenance of their own lives, heading for death. They felt the urgency of keeping themselves alive. The doctor's communication that the only chance of living would be HT leads to the difficult situation of having to decide about their own future, having the transplantation or not, aware of all risks. One participant describes:

I was already feeling bad. I think I was encouraged in this way... Let's say, whatever happens, there's no other solution; I felt encouraged, and it was easy to face it. I think that subconsciously it wasn't quite like that. Because who wouldn't be scared, you know? (P9).

Another recalls his anger and sadness:

When you get sick, you don't usually think about the worst possibilities. You think that you are going to a hospital, and then, when you get there, you will have a shot. Everything will be all right, you will go home and feel good, you know? But you never think that you're going to get there and hear that you will have to have a transplant; that your heart will be taken out because it's not working anymore; it's not going to work... when I remember, when I start thinking about it, I cry, you know? (P5).

The conversation with the doctor is decisive:

Then, he asked me: *Do you have children? Do you want to raise your children? This is your last chance: the transplantation.* Then I thought carefully and agreed (P4).

The time spent waiting for the new organ is described in detail by the participants. They wait for a new organ while life escapes from them.

The phenomenon of waiting opposes that of activity. While waiting, time is lived in its inverse direction, and it is qualitatively different from that lived in activity. While in activity we expand ourselves towards what is to come; in waiting, the future comes towards us. We wait until a predicted future occurs and becomes a fact⁽¹⁵⁾.

The patients wait until their future becomes a reality. They wait for an organ, for the heart of another person, the donor, so that the transplantation surgery can occur. It is a time filled with anguish, which is expressed by the uncertainty related to the outcome of the surgery, with the announcement of finitude: the patient may live or die. They stand still, powerless and with their lives put in suspension: they just wait.

Waiting, as described by a participant, is full of powerlessness and inactivity:

When you're hospitalized, you just lie there, waiting for the transplantation... waiting until a donated organ arrives. After three months, my situation was becoming worse and worse. (P2).

Others experience the frustration of several transplantation attempts:

They called me once; it didn't work out. I came again; it didn't work out again. Then, I came once more. The third time, it worked, and I was able to have it (P7).

HT provided the future of a different life which was not foreseen as a possibility. And, as a possibility, it pushed them ahead to the time that would come by means of the desired and performed actions, in such a way that they even perceived themselves as different people. It was a rebirth, as described by the reports:

Since I had the transplantation, I've felt wonderfully well. In everything, completely, I am another person. I felt well (P4).

Then, it all worked out, you know. I think the surgery lasted 7 or 8 hours, and from then, everything began to change, you know. I started to improve; after 4 days, I was able to get up with help, and since then, everything has improved (P5).

The present brings contentment:

I am very satisfied and content about the recovery that I've had. I thank the professionals' technology... it was so hard; this type of surgery that they performed on me. I am in such good shape that I look like I've been renewed (P6).

To others, the present future is lived in terms of the past, since improvement is delayed by a confusing and uncertain post-operative period. There are rejection problems; there is a possibility of recurrence of Chagas disease; there are post-operative complications. One participant describes:

I had open wounds on my leg. I came here, had a biopsy done, and it was Chagas disease. Since then, I've been well, thank God. Then, in 2001, there was another rejection, a slight one. Then, the medication was changed; I was here for a week and I was released: I went home. Now, I'm fine, thank God (P4).

The heart recipients attribute different meanings to taking possession of another person's organ. It is an extraordinary experience that is not part of their life expectations. The heart is a vital organ, traditionally seen as being the soul, that is, the body's breath. This view has a religious character and is existentially embedded in the perception of one's own body. The presence of life is identified from the heartbeat. Its popular conception is surrounded by an aura of myths, since emotions and feelings are viewed as coming from the heart. Hence, having another person's heart in *one's own body* is not a common experience; it requires some time for adjustment. It is a time lived that is filled with ambivalence: joy, at being alive; uncertainty, with regards to the fact that the heart may stop at any moment, since it showed all its frailty in the transplantation process; guilt, for being alive as a result of another person's death; and discrimination, since one perceives oneself as being different from others, and perceives that others see him differently. Despite these conflicts, all of them accept it as a gift, or a present. There are feelings of relief and happiness for being alive. There is also an attitude of humbleness in the face of life, and they are thankful to the people who donated their hearts.

Some regard the event as routine:

And then one day, the transplantation day came. Then I went down to the surgery, and the transplantation was done (P6).

Another patient empathizes with the donor and talks about him in a personal fashion.

They went to get the kidney. I know it was a 37-year-old man. The kidney and the heart belonged to the same person (P8).

To a third patient, the feeling of having lost his heart still remains four years after HT. His time lived in the present shows that he is another person:

You will always keep that in mind. That I live, today, I no longer live with my own heart; this is the case. It will never be the same thing. The heart, it beats fast, faster. You will never be what you were before (P5).

Two recipients manifested insecurity: something will happen at any moment, placing them again in a life-death situation:

You are doubtful, you know. The outcomes... I have read a lot about it. Death in one year (P9);

You feel like, it seems like a type of expectation. That something will happen, it's not, you know... Then it seems like you live kind of walking on a tightrope, you know? (P2).

Having one's heart transplanted makes one feel discriminated against, according to one recipient:

But the only thing I felt was prejudice... from my workplace. Because I went back to work after I'd been on sick leave for 3 years (P1).

To him, it was as if he had been marked. He supposes that the fact that the people around him knew about his transplantations would make them look at him differently, as if he were sick or in immediate danger of death.

TOPIC The conception of heart transplantation presented by patients with Chagas disease

The participants talk about what the HT experience meant to them. When analyzing what happened, they express themselves about the surgery, and the transformations which they have undergone as persons and in their perception of themselves.

To them, HT means a new chance at life. They refer to the experience lived as a *rebirth*. One recipient says:

I thought it was a new life for me, you know. I had been suffering a lot with the disease. It was killing me. Then, the opportunity of being transplanted arose. I had never seen this type of surgery work out so well as mine did. Nothing went wrong; everything was planned, everything went well. I woke up at the right time, and since then, I've been recovering more and more (P6).

To the patients, HT seems to be an exceptional occurrence. They know it is a high-risk and very complex surgery, both in physiological and technical terms. The perplexity felt results from such knowledge. They perceive the possibilities of life that are given to them. They are gifts. At the same time, when they perceive themselves living this fantastic experience, some also talk about the suffering that they have experienced as a result of the surgical procedure itself. One participant describes:

It's an indescribable experience. Very shocking, gratifying, painful. You get all hurt, but you're thankful. I can't explain. It's fantastic. You're a nervous wreck, but very thankful (P9)

Some do not refer to this period of the treatment process, as if it had never existed:

Then, you don't remember anything. You recall things gradually (P1).

They performed the transplantation, and it was not until 15 days after the surgery that I became aware of what was happening (P2).

The changes occurring after HT are the experiences of recovering life. Some believe that they have recovered health, although they know that they still have the infection and that they will have to undergo rigorous treatment for life. There is ambiguity of feelings in relation to oneself as being sick and, at the same time, healthy because HT returned to them to the well-being that had been lost due to heart failure.

Episodes of rejection and the occurrence of other pathologies are still a challenge to them. At present, one participant struggles with renal complications caused by immunosuppressants:

I will overcome this kidney problem, you know, and I am still alive (P2).

Others report the limitations imposed by HT: a strict diet and a lot of medication for the rest of their lives. One participant confesses:

We can't eat what we like most, we can't. But sometimes I still eat a little. I told the doctor about it, and he said: *M., don't abuse it.* But I sometimes go overboard a little... (P4).

The re-establishment of trivial activities, such as walking, breathing and speaking, lead them to recover autonomy. They perceive themselves differently in relation to their previous lifestyle. In this new life experience, returning to work is crucial. Work means reinsertion into normal life, into their places in society. It means self-fulfillment:

I'm planning to find a job and work. Work (P7).

To one recipient, her job is to return to her duties as a mother:

I take care of the house. I have four children. The oldest is 16 years old, one is 11, one is 10, and the other is 5. My son has a small problem, and I take him to a speech therapist's every week. I have to do everything. Thank God (P4).

Some resent discrimination at work:

You can't get a job anymore. You quit a job, and you can't find another. This is the bad part (P1);

It's hard enough for healthy people, and it's even more complicated when you are sick. I mean sick, you know, that you've had a transplant. People know that you've had a transplant and won't give you a job (P7).

TOPIC Care in the course of heart transplantation

This topic was manifested at different moments during the recipients' descriptions. In the ways to be with the

health care team, with their families and in the intentionality of taking care of others, influenced by all the care that they have received, they want, according to their possibilities, to take care of others too.

The recipients express gratitude:

When I was hospitalized, I said: not all mothers attend to us as the nurses in this hospital do. Mothers abandon us, and the nurses receive us so well (P7).

The time lived at INCOR is so intense that they begin to feel as though they live there. The institution feels like home:

I have been treated in this hospital since 1991, and they are the ones who have kept me alive. Chagas disease has caused all this, you know. Also, I have lost a 26-year-old brother. If you're not well cared for, the chances are really small, you know (P2).

The family is present by providing care and being cared for. Husbands, wives and children are mentioned in the statements regarding their concern and dedication to the recipient, and the latter wants, as his life project, to be concerned about them. One participant says:

Taking care of my children. In the past, I didn't really act as their mother. I mean, I couldn't do things for them. I can now (P4).

The reciprocity in giving care and being cared for appears in some descriptions. It is necessary to return the care and support received from roommates:

I will spare no efforts to do anything necessary to help. I will be able to help. Because I know how hard it is to face what I went through (P5).

DISCUSSION

The general themes of the experience lived during HT emerged from the participants' descriptions. In the phenomenological conception concerning the intentionality of conscience, every conscious act is directed toward an object, and every event is the spontaneous way of being in the universe. This is also the way by which things and experiences become significant to those who experience them⁽¹⁴⁾. The patients with Chagas disease who underwent HT described how they directed their conscience towards the maintenance of life during all HT phases: initially in a painful way, seeing life being extinguished little by little, then having to decide to undergo HT as the only way to preserve it; and finally as a revival, struggling to keep and enjoy their new life, still seeing themselves in a struggle.

In recalling the HT experience, they reported their fears, anguish, guilt, physical suffering, concerns, joys, and thankfulness for life and for the gift of receiving a new organ. They also reported their feelings about the extraordinary event of seeing themselves completely dependent, without hope at first, then in a situation of feeling free and open to a life of

opportunity, complicity and comradeship with nurses and doctors. They were discovered to be knowledgeable, although at an existential level, about the technical complexity of the procedures to which they were submitted.

Almost all of them are simple people, poorly educated and with few financial resources. However, they are aware of the meaning of having Chagas disease, and that HT means survival, but not a definitive cure. They know that, while they remain alive, they must depend on their own care as well as on that from health care professionals, the health institution and their families.

The findings in this study unveil the complexity and ambiguity of the experience lived, as well as awareness of the fact that, in spite of difficulties, there is still a future to be planned. They are not at all certain about the future, but there is a future. The time lived before, during and after HT is accompanied by the tension between *keeping oneself alive and accepting changes and living with them*. From the diagnosis of heart failure caused by Chagas disease, to experiencing an almost non-life, to agreeing to having their heart replaced, to waiting for a donor and experiencing anguish about the life that was lost so that they might live, until after the surgery, when they felt reborn, it is a continuous struggle. If their life before the transplant was simply to remain alive, it is now a struggle to hold on to what they have achieved: a normal life, although within a strict treatment regimen and care that will never cease for the rest of their lives

Although there are no data in the literature concerning the subjective experience of patients with Chagas disease who have undergone HT, it is possible to find common ground between the findings in this study and those in other investigations on HT as a result of other pathologies^(4,9,11,13). The latter describe, in a similar fashion, how HT involves a course of stressful events which produce the deep perception of the precariousness of one's existence. At the same time, it produces hope and opportunity for a new chance at life and a clear sense of new priorities: the recipients begin to value affective and social relationships in particular^(4,9,11,13). The strategies used by the recipients to deal with conflicts and difficulties after HT vary from exaggerated optimism to negation of the severity of the occurrence. Some adopt, in a positive fashion, constructive measures so as to obtain support from the health care team and their families, and to define goals and align themselves with their new reality⁽⁹⁾.

As regards the adaptation to a new life, working and playing a social and family role are some of the concerns of many participants in this study: from the mother who resumed her functions and motherly duties in relation to her children to the professional who struggles to return to work. These data also coincide with those in previous studies⁽¹³⁾.

The high level of satisfaction in relation to their current situation, which was described by all participants, even by those who presented and still present severe complications, is also a convergent finding with those described in the literature, being understood as the perception of the

patients who received a valuable gift: the extension of life that was being lost^(4-5,11).

Similarly, the belief of having recovered good health, as stated by some, despite the permanence of the trypansome in their body, can be interpreted in the belief that good health would be the absence of strange sensations, pain or discomfort. When overcoming the symptoms of the disease, the body, which had become *non-familiar* during the disease, is again *familiar*. Hence, people feel "cured" when they resume control over their lives and their bodies, returning to their usual activities, even when they continue to require treatment for chronic diseases⁽¹⁷⁾.

These health conceptions emphasize the phenomenological and existential meaning of the body: my body is my anchor to the world. Through my body, I live, act and perform my exchanges with the world around me⁽¹⁴⁾. In this regard, it is possible to understand that the participants, when stating that they had recovered good health and the normality of life with the heart transplantation, are talking about how they began to act, interact and live as they used to do before their heart disease. These recipients' perceptions can be interpreted as positive by some of the professionals on the care team; however, at the same time, with some concern due to the possibility of impairing adherence to treatment.

CONCLUDING REMARKS

By unveiling the meanings attributed by the patients to their experience, this study exposes subjective aspects of HT that had not been reported in previous investigations. Hence, the results achieved provide new possibilities to understanding the phenomenon of undergoing heart transplantation when one has Chagas disease. The patients' expression of the experience lived (their view of the disease, HT and the therapy, their difficulties and needs) contributes to the construction of the knowledge that nurses, doctors and other professionals must have in order to develop treatments and programs effectively targeted at patients and family members. This approach places patients in a central position in the follow-up and health care program, thus stimulating them to take a major role in their own care. Another crucial aspect is the importance of family participation in the care of the recipient: the data in this study indicate the need for special care to include relatives in educational and support programs for heart recipients.

This investigation presents the characteristics of a qualitative study: it does not intend to achieve generalization, but to understand the studied phenomenon at the site and time in which it is developed. The results suggest the need for further studies, in other regions of the country, and above all, investigations regarding patients' adherence to treatment, as well as on the role of family members and professionals in relation to individuals with Chagas disease during and after HT.

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