Repercussions on the daily living of post-heart transplantation patients

Repercussões no cotidiano dos pacientes pós-transplante cardíaco

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Abstract

Objective: To learn the repercussions on the daily living of patients that underwent heart transplantation.

Methods: A descriptive and qualitative study was conducted in a transplantation center in the Brazilian Northeast region. Nine patients who underwent heart transplantation participated in the study. Data were collected using the focus group technique, facilitated in four meetings. The excerpts of their statements resulted in two thematic categories: being a heart transplantation patient - before and after; and feelings and perceptions on heart transplantation.

Results: The people submitted to transplantation identified positive changes achieved after the surgery, but suffered with the countless prohibitions that directly interfered on their daily living; the limitations resulting from transplantation were highlighted and hindered patients from feeling effectively healed.

Conclusion: Participants recognized heart transportation as a solution for their clinical symptoms, but with a significant loss of autonomy that compel them to intensive adaptation efforts.

Resumo

Objetivo: Conhecer as repercussões no cotidiano de pacientes submetidos a transplante cardíaco.

Métodos: Trata-se de estudo descritivo, qualitativo, conduzido em um centro de transplantes do nordeste brasileiro. Nove pacientes submetidos ao transplante cardíaco participaram do estudo, tendo sido utilizada para coleta dos dados a técnica de grupo focal, facilitada em quatro reuniões. Os recortes de suas falas resultaram em duas categorias temáticas: ser transplantado cardíaco - o antes e o depois; e sentimentos e percepções sobre o transplante cardíaco.

Resultados: A pessoa submetida ao transplante identificou as modificações positivas obtidas após o procedimento, porém ressentiu-se com as inúmeras proibições, com interferência direta em seu cotidiano; as limitações decorrentes do transplante ganharam destaque e não permitiram que os pacientes se sentissem realmente curados.

Conclusão: Os participantes reconheceram o transplante cardíaco como uma solução para seus sintomas clínicos, contudo, com significativa perda de autonomia, obrigando-os a um intenso esforço adaptativo.

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Introduction

Heart failure is the main cause of hospitalization due to cardiovascular diseases, and the etiologies associated with it account for about 6% of the deaths registered in Brazil.(1,2) In an attempt to minimize the situation, heart transplantation is a surgical alternative used to treat heart failure not responsive to clinical and/or outpatient treatment, improving the expectancy and quality of life of patients suffering from this disease.(2)

However, the survival rate after heart transplantation decreases as the years since the procedure go by, and this rate suffers the influence of the post-surgery monitoring of patients. Hence, heart transportation outpatient care plays an important role in the maintenance of the well-being of heart transplantation patients, favoring longer survival time with better quality of life, which is correlated to the absence of heart failure symptoms that allows resuming basic and instrumental activities of daily living and a potential return to labor activities.(3)

Nonetheless, this resumption demands a wide range of adjustments and patients must follow several instructions to keep their well-being and prevent complications, mainly in the initial post-transplantation months. It demands changes on the daily living that, in turn, reduce the rage of personal decisions due to a set of instructions and rules characterized by standardization and impersonality. The work of a multidisciplinary team is crucial in this matter to assist patients in their adjustment to the new life.(4,5)

The daily living of those submitted to transplantation is different from that of people who have not undergone the procedure, because of the excessive care required to prevent infection, the healthy and proper food demanded, weight maintenance and continuous administration of medication sharply on time. Thus, the participation of the team in health promotion measures is of special importance,(4) as this care is effectively required and has strong social impact on the lives of those submitted to transplantation. However, few studies, mainly at national level, approach this phenomenon, showing the need for promoting research on this topic.(5-8)

A consensual point in the existing studies on heart transplantation is that life itself gives a sense to the daily living; however, complex situations and new concerns related to the condition of being a heart transplantation patient come about. In that context, the existence of social, professional and, above all, spiritual support is crucial to meet the patients' aspirations, as self-care maintenance brings positive impacts on their daily living, improving the quality of life even of those with over five years of heart transplantation.(5-9)

Understanding the daily living of patients submitted to transplantation implies understanding how these people relate to the guidance provided by the health team and the heart transplantation itself. In this sense, the objective of this study is to learn the repercussions of heart transplantation on the daily living of individuals submitted to the procedure.

Methods

This was a descriptive study with a qualitative approach, developed at the unit of heart transplantation and failure of a hospital in Ceará, which is specialized in cardiopulmonary diseases. The unit had a multi-disciplinary team and booked medical visits following the service protocol, as follows: weekly up to one month of transplantation after hospital discharge; every two weeks until the third month after transplantation, and then on a monthly basis until one year after the procedure, when patients start going to hospital every three months. In order to ensure the medical visit quality, the hospital established the limit of 12 patients a day, regardless the length of transplantation.

Based on that protocol, the study participants were selected according to the following criteria of inclusion: having been submitted to heart transplantation for up to six months and being in regular outpatient care monitoring. The post-transplantation period was selected due to the significant volume of information imposed by the multidisciplinary team, which required the transplantation patients to make continuous adjustments to their daily living. After that period rules are relaxed, establishing a more independent and autonomous behavior of the patient. After the selection, patients presenting unsatisfactory clinical conditions like admission in an intensive care unit, isolation for use of medication due to graft rejection and damage to the consciousness level, were excluded.

In 2012, 29 patients were submitted to heart transplantation. Of these, 14 had undergone the procedure within six months, according to the data collection period, and five patients missed the required clinical conditions to participate in the study due to clinical instability and need for specific care, as aforementioned. Hence, nine participants were identified to the study, of which seven were men with a mean age of 40.8 years (± 8.8 years). The anonymity of subjects was preserved identifying participants with letters followed by a cardinal number.

Data were collected in January 2013, using the focus group technique.(10,11) The informal nature of discussion and small size of the group allowed in-depth information collection, as participants felt at ease to talk about their experiences. Although this is a quick and low-cost technique for data assessment and collection, its scientific character results from the systematization of groups that facilitated analyzing the statements by participants.

The focus group was organized in 9-patient groups that participated in the four meetings held and previously booked. The focus group started at 9 am, lasting 60 minutes on average. There was a facilitator who started, conducted and closed the session, additionally to an observing rapporteur in charge of recording the participants' speech and non-verbal language, and analyze the focus group conduction.

The following script of guiding questions was employed for discussions: (1) describe the experience of being a patient of heart transplantation; (2) comment on your daily living as a heart transplantation patient; (3) talk about the instructions provided by the multidisciplinary team. The first question was used to conduct the first and second meetings because of the need for making room to the debate on pre-transplantation period that was widely quoted as a comparison element; the second and third questions, in turn, were developed in the third and fourth meetings.

The questions have the potential to foster the active participation of the patients selected, besides guiding the formulation of new questions based on the oral expressions. In order to deepen the reflection about the repercussions of heart transplantation on the daily living of patients, sometimes the facilitator returned to some questions proposed adding new contributions by the participants, and improving the understanding about implicit meanings.

The meetings were recorded and then transcribed. Based on transcriptions, the statements were organized into units of meanings that, after categorization, led to two different categories: being a heart transplantation patient - before and after, and feelings and perceptions about heart transplantation.

Hermeneutic principles oriented the understanding and interpretation of speeches favoring the suspension of characteristics inherent to individual experience, bringing up life experience, as suggested by Dilthey. According to the hermeneutics, as a methodological resource, the whole can be understood when decomposed into parts that preserve shared meanings. The decomposition of speeches highlighting implicit meanings, and further reconstitution based on a whole that is elaborated, allowed understanding more relevant aspects that assisted deepening the proposed object of study.(12,13)

Guided by these foundations, the authors took significant excerpts of the participants' speeches and, after recomposing these, obtained five units of meaning as follows: life before heart transplantation; plans for the future; social isolation; behavioral restrictions; feelings and perceptions about the team and guidance. Further, these units gave rise to the following thematic categories: being a heart transplantation patient - before and after, and feelings and perceptions about heart transplantation.

The development of the present study complied with national and international ethical guidelines on research involving human subjects.

Results

Being a heart transplantation patient: before and after

Based on the statements by the study participants and their experiences prior to transplantation, it was observed that for most cases patients perceived the indication of heart transplantation as a possibility for restoring their health status. This fact can be observed in the following statement: "*I was in a critical situation, I was 70% dead and 30% alive*". (N1).

In face of the uncertainty if the expected organ would arrive on time and of the development of disabling signs and symptoms, some patients found the necessary power to manage the situation in spirituality. That happened before and after the surgery with different motivations for both periods, as shown in the following statement: "*Jesus has always given me power to stay without my kids*". (E16).

After the heart transplantation, new situations emerged in the patient daily living and spirituality remained a means of motivation to cope with the changes in several aspects of their lives. Some patients became solitary and present some deficit when it comes to socialization, due to the requirements resulting from treatment, reinforcing the need for being adjusted to the social environment by engaging in groups or getting closer to spiritual matters.

Some adjustments were also related to following the therapeutics. Among the difficulties to adhere to the post-transplantation required care, patients highlight limitations related to self-care as this involved adhering to behaviors which used to be unfamiliar to them: "*It's hard because we want to do the right thing*". (O2).

After overcoming the initial difficulties, the participants started resuming or planning activities of daily living, including work, which was a positive factor as it is an important element in people's lives, often improving the well-being and the health of individuals submitted to transplantation. Many statements reflect the patients' expectation to resume their labor activities as an alternative to the recovery of their identity as healthy individuals. This is shown in the following statement: *"I really had to work"*. (P8)

Feelings and perceptions about heart transportation

In the period prior to the procedure, transplantation was perceived as the cure to all the ills. However, after transplantations patients faced several limitations and difficulties to maintain the required care, including the feeling of losing autonomy.

The individuals submitted to transplantation recognized several changes and said as follows: "*I have completely changed psychologically and physically". (K3).* They found themselves subjected to several limitations and difficulties to maintain the required care, including the feeling of having lost their autonomy, as transcribed: "*There is nothing we can do, everything we want we just can't*". (K7).

Moreover, patients found difficulties in taking the care recommended by the team, and it was observed the objective interference of the health professionals' instructions on patients' social habits. These were often imposed, with no plausible explanation to facilitate understanding and, thus, accepting the rules. Some patients vehemently commented on this fact: "*It is difficult to be isolated at home; I have one little granddaughter and she just stayed at the doorstep*". (Q15)*; "This part will be really hard, I have young kids, I haven't seen them for almost five months"*. (M5).

Despite all difficulties, the organs recipients felt happy, thankful and victorious for having survived to the heart transplantation. The feeling of gratitude and recognition of a new life is found in the statement by many transplantation patients, with visible feelings of victory: *"I thank for being alive"* (N8)*; "It is a new life to me"* (J1)*; "I was born again"* (R2).

The statements of heart transplantation patients show that, despite the strict and continued treatment to keep their quality of life and the organ feasibility, the feeling of satisfaction for being alive and having a longer survival expectancy prevail.

The comfort of no longer living with the limiting signs of heart failure, of having the right to planning the future and, above all, of having the certainty that they had their right to be happy restored were the prevailing elements on the statements of these patients.

Discussion

The daily living of patients submitted to heart transplantation is characterized by new situations that involve adjustments by the family and the social network surrounding them. Understanding this issue, we believe that the participation of these other elements in further studies would be important to better understand this phenomenon, as this study was limited to the patients' perceptions.

A wide range of physical and psychosocial manifestations were found in the period prior to and after heart transplantation. It is in this context full of dualities (life/death, health/disease) that the path to be followed by individuals waiting for or submitted to heart transplantation is built.

Heart failure is one of the main causes of hospitalization in Brazil and in the world,(14,15) with symptoms that bring about significant limitations to the daily living of those waiting for transplantation. This perception of losing vitality is often associated with lower autonomy and a higher level of impairment for self-care. As the disease develops, patients often wait for the organ in the hospital, which results in social isolation and feelings of impotence and vulnerability.

After the phase of uncertainties about the procedure, the transplantation patients recognize the situation as complex, and report difficulties regarding adaptation to the social environment as they stay a long time far from their peers, in the beginning in compliance with the guidance provided by the multi-professional team and, then, for fear. Nonetheless, other studies agree on the significant improvement of patients' quality of life resulting from the presence of their caregivers and of the social, family and spiritual support.(5-9)

There was also some difficulty regarding adherence to post-transplantation care, although patients acknowledge its importance. Since adherence is defined as the degree of coincidence between the behavior of a person regarding taking medicines, following a diet and/or changing their lifestyle, and the recommendations by a health professional,(16) the limited health status damages the achievement of adherence goals and demands changes and adaptations during the whole process of waiting for the transplantation or after it.

As corroborated by a survey carried out by Sadala and Stolf,(8) transplantation patients report some difficulties regarding self-care. According to the authors, the practice demands adherence to unusual behaviors, thus requiring more preparation during the pre-transplantation period. Despite the difficulties and intensive adaptation efforts, the study by Aguiar et al.(4) supports our findings as it also shows that the transplant patients interviewed strictly followed the required treatment to reach good quality of life.

Supplementing these results, Buendía et al.(17) restate that heart transplantation improves the functional capacity of patients that adhere to the treatment. However, they only feel to be healthy after a certain period of treatment, when they start performing activities of daily living in a normal way, including working. This context of return to everyday and labor activities poses many challenges. According to the study by Jalowiec et al.,(18) only 26% of the patients submitted to transplantation were working one year after surgery and faced many difficulties in the rehabilitation period.

These adaptations involve several feelings. As presented in the study, patients experienced happiness, gratitude and victory as they overcame the waiting phase and could envisage a new day and a new life. These feelings are common among patients submitted to heart transplantation in other countries, where gratitude, satisfaction and resignation alternate. Patients show gratitude when their health considerably improve, but feel resignation when complications or side effects occur due to the lack of information or support.(19) On the other hand, negative feelings such as sadness, have also been reported in another study,(18) characterizing this path of "being a transplantation patient" as complex and controversial, but which generates life.

Conclusion

People submitted to heart transplantation identified positive changes after the procedure, but suffered with the countless prohibitions that directly interfere with their daily living. Limitations resulting from transplantation were highlighted and prevented patients from feeling really healed, although recognizing the procedure as a solution to their clinical symptoms. There is a significant loss of autonomy that obliges patients to intensively endeavor to be adjusted. However, those efforts culminate in the adherence to the guidance by the team and to the understanding that maintaining care is important to maintain life, which makes them happy and thankful. It is worth mentioning that inclusion of patients that were submitted to the procedure within up to six months was a limitation to the study. In that period, the heart transplantation patient, fearing the procedure failure, put all their efforts to adhere to the pharmacological and non-pharmacological measures, which makes us consider if this commitment with guidance provided by the team is persistent and a reflex of deeper awareness about the adoption of a new lifestyle.

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Collaborations

Vasconcelos AG, Pessoa VLMP, Menezes FWP, Florêncio RS and Frota MXF contributed with the project design, data analysis and interpretation, drafting of the article, relevant critical review of its intellectual content, and final approval of the version to be published.

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