

## Original Article

# The Outcomes of Heart Transplantation: A Qualitative Study

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### ABSTRACT

**Background:** Heart transplantation has heartened many patients who suffer from end-stage heart diseases. Nonetheless, it is associated with many different outcomes which vary according to the immediate context. **Objectives:** This study aimed to exploring the outcomes of heart transplantation in a sample of Iranian patients. **Methods:** This qualitative study was done in 2014–2016 by using Graneheim and Lundman’s approach to qualitative content analysis. A purposeful sample of heart recipients was recruited with maximum variation from hospitals of Tehran, Iran. Data were collected by semi-structured interviews. Data collection was continued until the categories were saturated. In total, seventeen interviews were done with fifteen heart recipients. **Results:** The main theme of the study was “Living under the perfect storm of problems.” The four main categories of this main theme were financial distress (with the subcategories of the shadow of financial strain on life, the inefficiency of financial support systems, struggle for managing the expenses), living with the consequences (with the subcategories of physical crisis, inability to perform roles, psychological problems), greater commitment to one’s own health (with the subcategories of accepting responsibility for health, moving from ignorance to search for information), and tendency to spirituality (with the subcategories of reinforcement of religious beliefs and values, and gratefulness to the donors). **Conclusion:** During the posttransplantation period, heart recipients encounter difficult conditions, and so, they need to receive stronger support from healthcare organization and authorities. Besides, transplantation-associated financial problems make coping with transplantation more difficult, and hence, appropriate measures are needed to alleviate their financial problems.

**KEYWORDS:** *Content analysis, Heart transplantation, Iran, Outcomes, Qualitative study*

## INTRODUCTION

Heart transplantation is a difficult operation and is associated with different types of risks. Patients who are candidates for transplantation are primarily placed in the waiting list. During the waiting period, they and their family members experience considerable stress due to problems such as frequent hospitalizations and heavy financial strains.<sup>[1]</sup> Besides, the happiness and hopefulness related to the placement in the waiting list<sup>[2,3]</sup> are usually replaced by despair and frustration due to lack of transplants, disease aggravation, and other problems.<sup>[4]</sup> Furthermore, while the heart problems of patients who receive a transplant are alleviated, they

develop new posttransplantation problems. For instance, they will need intensive care services after the operation which may negatively affect them physically, mentally, and psychologically.<sup>[3,5]</sup> Moreover, they may experience negative feelings such as fear, depression, and despair.<sup>[1,6]</sup> The results of several phenomenological studies also revealed that after heart transplantation, patients undergo different experiences such as calmness, depression, despair,<sup>[4]</sup> new concerns, contradictory feelings, negative

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reactions from others, closer relationship with God,<sup>[2]</sup> as well as occupational, financial, and educational problems.<sup>[7]</sup> Some phenomenological studies mostly focused on issue such as psychospiritual experiences of heart recipient.<sup>[2,6]</sup> Some also dealt mainly with general experiences about heart transplantation.<sup>[4]</sup> In other words, they failed to specifically address the physical and psychosocial outcomes of posttransplantation period. Hence, this question arose that “what are the physical and psychosocial outcomes of heart transplantation for these patients? And how patients experience these outcomes?”

### Objectives

The present study was done to explore the physical and psychosocial outcomes of heart transplantation.

## METHODS

### The study design and participants

As part of a larger study into the process of coping with heart transplantation, parts of data were analyzed using Graneheim and Lundman’s approach to qualitative content analysis.<sup>[8]</sup>

Sampling was done purposefully from January 2015 to June 2016 of people who have had heart transplant. Attempts were done to maximize the participant’s variation regarding their age, gender, and financial status. The participants were patients who had undergone heart transplantation. The inclusion criteria were age more than 18, being able to speak in Persian language and agreement for participation in the study. Patients with apparent psychological problems were not included. Accordingly, we referred to the Imam Khomeini, Dr. Shariati, and Masih-Daneshvari hospitals (all in Tehran, Iran) and created a list of patients who had undergone heart transplantation. Then, we telephoned the patients in the list and invited them to the study. If agreed, they were asked to determine the preferred time and place for interview.

### Data collection

Data collection was performed by the first author through conducting semi-structured interviews. The first participant was recruited from the cardiac care clinic of Imam Khomeini hospital. He had undergone heart transplantation 1 year before recruitment to the study, had a senior secondary diploma degree, had experienced a good posttransplantation period, and seemed to be a good key informant. He preferred to be interviewed in an interview room located in Tehran faculty of nursing and midwifery, Tehran, Iran. The interviews were mainly started by asking this question, “Please tell the story of your posttransplantation life from the 1<sup>st</sup> day up to now.”

Then, a series of questions was asked based on the aims of the study and the participants’ shared experiences. These questions included, but not limited to, “What problems did you experience after the transplantation? What measures did you take when facing the problems? Besides these questions, we used probing questions such as “Can you explain more about this?” and “Can you clarify this?” The next participants were selected to complete the categories emerged. Data collection was finished when all categories were fully developed and no new category was generated from the data. The length of the interviews ranged between 30 and 90 min, depending on the participants’ endurance and interest. All interviews were recorded by using a MP3 recorder. In total, 17 individual interviews were done with 15 participants.

### Ethical considerations

This research project was approved by the Ethics and Research Committee of Tehran University of Medical Sciences, Tehran, Iran (IR. TUMS. REC.1395.2504). We entered the study setting after obtaining necessary permissions from the administrators of the setting. The aim of the study was explained to the participants, and their written consent was obtained. They were assured that the findings would be reported anonymously and their withdrawal from the study would not affect the course of their treatment. Participation in the study was voluntary and the participants were free to withdraw from the study. Moreover, the participants were informed that their voices would be recorded just for the purpose of the present study.

### Data analysis and trustworthiness

Data analysis was started immediately after the first interview and continued simultaneously with the process of data collection. The Graneheim and Lundman’s approach to qualitative content analysis<sup>[8]</sup> was used for data analysis. Accordingly, the research team listened to the interviews for several times and made a verbatim transcript of them. Thereafter, interview transcripts were perused frequently to obtain a general and precise understanding about the data. Then, the sentences which contained important points about the outcomes of heart transplantation were identified as the units of analysis. For instance, this sentence was determined to be a unit of analysis: “I came here for surgery on Saturday. They told me that I should pay three million Tomans (almost \$750) to the hospital at the time of hospitalization.” Then, the expression “Paying three million for hospitalization that was too much” was extracted from the sentence and determined to be a meaning unit. After that, the meaning units were condensed, abstracted, and coded. For example, the meaning unit of “paying three million

Tomans (almost \$750) for hospitalization that was too much” was condensed to “paying the heavy costs of the surgery” and labeled with the code of “facing the heavy costs of the surgery.” Thereafter, the codes were compared with each other and those with similar content were grouped into categories. As an example, the codes of “facing the heavy costs of surgery” and “heaviness of treatment-related costs” were grouped around the subcategory of “the shadow of financial strain on life.” Coding and categorization continued until the main theme of the study was generated.

Graneheim and Lundman recommended three criteria for establishing the data trustworthiness.<sup>[8]</sup> These criteria are credibility, dependability, and transferability. To ensure the credibility of the findings, research team attempted to identify and put aside our suppositions and prevent them from affecting our interpretations of the data. Maximum variation helped us to gain richer information. Besides, several participants were asked to determine the level of congruence between our generated codes and categories and their own experiences. Research team also discussed about the generated codes and categories until reaching a general agreement. Other techniques which we used to establish the credibility of the findings consisted of selection of the best quotations as the meaning units, prolonged engagement with the participants and the data, concurrent data collection and analysis, and trimming the irrelevant data. On the other hand, the dependability of the data was established by asking a qualitative research expert – who was external to the study – to express his understanding of the data. His understanding was similar to ours. Furthermore, we used negative cases in some instances. Research team attempted to maximize the transferability of the findings through providing thick descriptions of the immediate context, the process of sampling, the characteristics of the study participants, as well as the processes of data collection and analysis. Finally, the study extracted categories were provided to two heart recipients who were external to the study. They confirmed that our findings were similar to their experiences.

## RESULTS

Participants in this study were 15 patients (male = 13, female = 2). The maximum and minimum waiting time was 18 months and 5 days, respectively. None of the participants were unable to return to their prior work. The mean age of participants was 43.4 years with a mean of 19.49 months passed from transplantation.

During the process of data analysis, the main theme of “Living under the perfect storm of problems” was abstracted. The main categories of this main theme were

financial distress, perceived physical and psychosocial changes, greater commitment to one’s own health, and tendency to spirituality. These categories are explained in what follows.

### Financial distress

The subcategories of the financial distress were the shadow of financial strain on life, the inefficiency of financial support systems, and attempts for managing the expenses.

#### *The shadow of financial strain on life*

The participants suffered from considerable financial strain due to the heavy costs of treatments, medications, transportation, dietary regimens, and diagnostic procedures. Such a financial strain had affected other aspects of the participants’ lives and reduced their quality of life. A male participant (P) who was engineer and seem to have enough income said: “How can a transplant recipient afford all these huge costs? Should he sell his house? What should we sell to pay the costs of treatments and medications?” (P. 4).

Some of the participants had difficulties in paying the costs of therapeutic and diagnostic procedures (such as periodic laboratory tests, echocardiography, and angiography) and even transportation. Consequently, they had managed to either receive these services with delay or avoid receiving them. A male participant who had a child received an income of 800000 Tomans (\$200), lived in a rented house, and had a poor financial status noted: “Currently, I need to pay 1 million Tomans per month (\$250) while I can only afford my medications. The weekly costs of transportation and laboratory tests are too heavy something around two hundred Tomans (\$50). I am under heavy strain” (P. 1).

Illness- and treatment-related costs in addition to the household expenses were too heavy for the participants that they could not afford the costs related to the transplantation-specific dietary regimen. A female participant with two children whose husband was a self-employed worker with low income said: “I can barely afford the costs of treatments and medications. Yet, they say that I should follow a specific regimen. Well, I cannot afford its costs” (P. 10).

#### *The inefficiency of financial support systems*

Another subcategory of the financial distress was the inefficiency of financial support systems such as insurance and governmental organizations. Most participants had experienced problems in dealing with these systems. For instance, insurance organizations neither easily approved posttransplantation medications nor facilitated their retirement. Moreover, they paid these patients’ monthly salaries with delay. A male

participant who had three children received a retirement income of 800,000 Tomans (\$200) and lived in a rented house noted: “I referred to the insurance organization for receiving disability-related services. They said that I cannot retire because I have paid insurance premium just for several years. Only God knows how often I have referred to this organization and how much I have cried” (P. 13).

#### **Struggle for managing the expenses**

When they found themselves in financial disarray, most participants attempted to develop and use strategies to manage their financial problems. Their strategies were mostly borrowing money and selling assets such as car, house, or land. A male blue-collar worker who had undergone heart transplantation before the Iranian healthcare system reform plan and had paid a high cost for the surgery said: “At the 1<sup>st</sup> days of my hospitalization, I borrowed money from my brother-in-law. I had already sold my car. Thereafter, I sold my house. Our household expenses are currently covered by the money of that house” (P. 2).

Some of the participants tried to manage their costs by avoiding buying unessential things and going to unessential journeys and attempted to use free domestic medications. Some of them had also decided to live with their relatives to cut their costs. A married young man said: “I have reduced a series of extra costs; for instance, I use medications made in Iran and avoid travelling. Previously, I used to buy two sets of cloths yearly while now, I buy just one set each 2 years; otherwise, I cannot afford my costs. Moreover, I integrated my family into my mother’s family to cut some costs” (P. 6).

#### **Perceived physical and psychosocial changes**

The subcategories of this main category were physical crisis, inability to perform roles, and psychological problems.

##### **Physical crisis**

Before heart transplantation, most participants had suffered from physical health problems such as digestive disorders (such as constipation), inability to eat, respiratory problems, neuromuscular dysfunction, and sleep disorders. Most of these problems persisted after the transplantation. Some of the participants also developed cytomegalovirus infections due to the use of immunosuppressive agents. Three months after heart transplantation, a male victim of chemical warfare stated: “I got diarrhea after the transplantation. Currently, I experience attacks of nighttime muscular spasm. Sometimes, the pain is so severe that awakens me. Now, I have developed viral infection and they said that I need to be hospitalized to receive injection drugs;

otherwise, my transplanted heart may be rejected” (P. 1).

##### **Inability to perform roles**

Patients with heart failure cannot efficiently perform their roles either as a parent in a family or as a citizen in a community, and hence, they become upset and worried. Similarly, after the transplantation, they may feel disabled due to their inability to perform their familial, professional, and social roles. Such feeling of disability can be more severe among patients who are responsible for covering household expenses. A male patient with three children said: “The man is not a man when he does not work, and could not pay his living expenses. Well; I become really upset because I cannot do my duty. I have a bad feeling because like before, I could manage my life” (P. 3).

##### **Psychological problems**

Heart transplantation is associated with different psychological problems. Our participants were severely upset and impatient due to the abundance of visitors and the intrusion of their privacy. They had experienced different problems before receiving a transplant and thus needed calmness after transplantation. Consequently, they avoided going to crowded places, were reluctant to see visitors, and preferred to stay in a calm and comfortable environment. A man who was previously a taxi driver said: “Each day, a lot of people with different temperaments got into my car. I worked in the crowded streets; nonetheless, I wasn’t so impatient. Currently, my relatives know that I’m too impatient and cannot tolerate crowdedness and noisiness” (P. 15).

Another posttransplantation psychological problem was great worry, particularly about the future. Most of the participants were extremely worried about their career prospect, household management, survival, and medication procurement. A patient who had undergone heart transplantation 5 months before the interview stated: “I don’t know how my situation will be after 1 year. What will happen to my family if I die? They have said that they won’t allow me to go back to work. Then, what should we do? What about income? What will happen to our life?” (P. 6).

##### **Greater commitment to one’s own health**

This category consisted of the following two subcategories: accepting the responsibility of health and information seeking.

##### **Accepting responsibility for health**

Among the posttransplantation responsibilities of transplant recipients are to accept responsibility for their own health, value it, accept the transplant, and care for the transplanted heart. Most of the participants attached great importance to their health and were worried about

developing transplant-related problems and going back to their pretransplantation conditions. Accordingly, they attempted to strictly adhere to self-care activities, treatment and dietary regimens, and the prescribed physical exercise programs. A male participant who had undergone heart transplantation 7 months before being interviewed said: “At the first posttransplantation day, I didn’t allow my wife to touch me because I didn’t want to develop viral infection. I cancelled all my visits with the visitors. I know that any viral infection can cause transplant rejection. Currently, I actively perform physical activities and adhere to dietary regimen as much as possible. I don’t like to become ill again. I feel responsible toward this heart and should care for it properly” (P. 2).

On the other hand, some of the participants were unable to adhere to their treatments due to lack of family support. A widowed man who had two children mentioned: “My daughter is alone at home and I can’t leave her alone and go outdoor for physical activity or walking. My doctor said that I need to do physical exercise; but in my current situation, it is impossible” (P. 1).

#### *Information seeking*

Unawareness of posttransplantation health care was associated with negative consequences for some participants. Some of the participants who lacked information about dietary regimen had developed either obesity or slimness. On the other hand, some participants lacked information about their medications and thus had changed the dosages of their medications. An illiterate patient who was from suburban of Tehran and had been hospitalized 2 years after the transplantation due to decreased cardiac function mentioned: “I should travel to Tehran for buying my medications. Such a long trip is difficult for me. This time, I decided to cut some pills into two and take half of a pill instead of a complete one. After a while, I developed shortness of breath. Therefore, I came here (i.e., to hospital) and they said that my heart is in problem.” (P. 8).

Those participants who valued their posttransplantation health attempted to seek and acquire information – from different sources – about transplantation, its complications, dietary and treatment regimens, and permitted level of physical activity. A patient with primary education expressed: “Currently, I pay careful attention to health programs on television, particularly programs on the heart. Besides, I ask my questions from nurses and physicians. I’m very interested while I wasn’t so previously” (P. 5).

#### *Tendency to spirituality*

The two subcategories of this main category were the reinforcement of religious beliefs and values and gratefulness to the donors.

##### *Reinforcement of religious beliefs and values*

Some participants believed that heart failure and subsequent heart transplantation were God’s will. Such a belief had provided them with more inner peace. They considered their reliance on God and praying as the main reason behind their successful transplantation. Most of these participants noted that they had not had such strong religious beliefs before transplantation. A patient who had undergone transplantation 1 year before the interview mentioned: “Previously, I held no such strong religious beliefs. One night when I was severely ill, I started talking with a saint. I told him that if I find a heart, I will pay his honor a visit. Just several days later, they called me and said that a heart had been found for me after transplantation, I went on pilgrimage for visiting his holy shrine and thanked him” (P. 13).

Some of the participants also believed that God is testing them by the illness. A married woman expressed: “God is testing me. He provided me with a heart. I rely on Him. I have entrusted myself to Him. Whatever He wills, it will happen” (P. 7).

##### *Gratefulness to the donors*

Most of the participants acknowledged and appreciated the donor’s organ donation through saying prayer and asking forgiveness for them from God. They were unhappy over the fact that their lives were saved by the death of another person. They attributed this to God’s will and attempted to acknowledge this practice by gifting pacemakers to other patients, joining organ donation campaigns, and encouraging organ donation. A male patient quoted: “The first thing I did after hospital discharge was to cook votive food and distribute it among the neighbors for the sake of the donor. I intend to do this every year. Moreover, I joined the organ donation campaign and encourage others to do so” (P. 3).

Besides, the participants acknowledged the donor families’ help and attempted to do something to alleviate their pains. For instance, some of them considered themselves as a member of the family donors and established close family relationships with them. A male participant who had endured a short waiting period and had undergone heart transplantation 3 years before the study noted: “I’m very glad about having relationships with the donor family. They are like my own family. They brought me back to life. I owe to them” (P. 9).

## DISCUSSION

Study findings showed that financial distress was among the most important problems experienced during the process of heart transplantation. Financial distress rooted in preillness time and was turned into a crisis during the process of heart transplantation. Farsi *et al.* also reported that patients who undergo bone marrow transplantation suffer from the shortage of financial resources.<sup>[9]</sup>

The study participants were under considerable financial strain due to both treatment-related costs and household expenses. Paying out-of-pocket healthcare costs, particularly the costs related to immunosuppressive agents, can significantly affect organ recipients' ability to spend a normal life.<sup>[10]</sup> Despite the fact that in Iran, domestic medications are free for patients who suffer from specific health conditions, our participants still had problems in paying treatment-related and household expenses. Some of the studies showed that in some countries, patients who are candidates for transplantation are assessed financially and referred to support systems.<sup>[10]</sup> However, in our country, patients are usually just assessed medically. Such failure to financially assess and support organ recipients can cause different physical, financial, and psychological problems for them.

Another finding of the study was the inefficiency of support systems (such as insurance organizations) so much so that most participants were concerned about paying their healthcare costs or early retirement. Such concerns can negatively affect posttransplantation survival.<sup>[3]</sup> Moreover, postdischarge unmet informational, financial, and support-related needs of patients can cause them anxiety and emotional problems, undermine their physical and mental health, and limit their coping abilities.<sup>[11,12]</sup> Ghiasvand *et al.* also reported the ineffectiveness of the National Insurance Program in preventing patients from experiencing treatment-related financial distress. They also reported healthcare authorities and policymakers' inattention to develop appropriate insurance-related strategies as the main reason behind the ineffectiveness of the Iranian Insurance System in supporting heart recipients.<sup>[13]</sup>

We also found that the participants attempted to manage their expenses through selling their assets, doing financial planning, borrowing money, and avoiding the purchase of unessential things. Raiesdana *et al.* also noted that heart recipients manage their financial problems and budget deficit through economizing on daily expenses and working harder for having higher income.<sup>[3]</sup>

Strategies such as financial planning and avoiding the purchase of unessential things may be effective and

helpful both in short- and long-term periods; however, selling the assets and borrowing money are ineffective long-term strategies that can cause patients damaging consequences and negatively affect their and their family quality of life.

Another posttransplantation outcome was physical crisis. Most participants reported physical problems such as muscular spasms, diarrhea, and skin rash. These problems are mainly the side effects of taking immunosuppressive agents. Patients usually think that all of their physical problems will be resolved after heart transplantation. However, after transplantation, they may experience different problems due to their posttransplantation critical conditions. Misconceptions about the alleviation of all problems after the transplantation might prevent them from effectively coping with posttransplantation problems.

Another experience of heart transplantation was inability to perform roles. Previous studies also reported ineffective role performance as the consequence of heart problems.<sup>[14]</sup> Probably, these patients lose their feeling of being useful for their families and community and feel that they are no longer able to fulfill their responsibilities effectively. It is noteworthy that public attitude toward the physical ability of these patients can affect their ability to perform their roles. Such misconceptions can give the recipients a sense of ineffectiveness. For instance, people may think that heart recipients can experience a sudden death, and thus, they avoid employing them or delegating responsibilities to them.<sup>[6]</sup> Accordingly, supportive systems need to strongly support these patients.

We also found that heart transplantation can be associated with psychological problems. Previous studies also showed that the transplant recipients usually become impatient<sup>[6,7,15]</sup> and patients develop mood disorders.<sup>[16]</sup> Such psychological problems might not only be attributed to the fact that these patients still suffer from a wide range of problems but also to the fact that they should adhere to strict dietary and treatment regimens.<sup>[9]</sup> Consequently, providing professional psychological counseling to these patients seems clearly essential.

Study findings also indicated that another outcome of heart transplantation was greater commitment to one's own health. It seems that severe pretransplantation physical problems cause recipients to have close adherence to the transplant and treatments. On the other hand, they feel responsibility toward donor families and feel that the transplant is a trust for the donors, and thus, they need to carefully protect it. Other factors such as

the symptoms of the illness, the atmosphere of clinical settings, and the type of treatment regimen can also contribute to treatment adherence.<sup>[17]</sup>

Most of the participants lacked transplant- and treatment-related knowledge and thus attempted to acquire necessary information to perform self-care activities effectively. Probably, lack of effective patient education programs requires patients to personally seek for health information. Inefficiency of healthcare and patient education systems in educating patients during the course of their hospitalization require patients to personally seek for information after hospital discharge.<sup>[18,19]</sup> It seems that healthcare providers pay no attention to patients' preferences regarding information seeking.

Tendency to spirituality was another consequence of heart transplantation. The participants had relied on God and attempted to manage their problems with recourse to the saints. They owed their lives to the donors and attempted to appreciate them through doing good things for the sake of them and establishing relationships with their families. The Holy Quran also says, "And when some hurt touches man, he cries to his Lord (Allah alone), turning to Him in repentance" (Sura Az-Zumar, Verse 8). Previous studies also showed that religious beliefs and rituals help patients cope with their conditions more effectively.<sup>[18,20]</sup> Perhaps, religion and spirituality guide people's thinking about the purpose of life which consequently affects their evaluation of daily life events.<sup>[20]</sup> Faith in God can improve the management of emotions and difficult situations, facilitate coping with heart failure,<sup>[3]</sup> resolve post-transplantation limitations and problems, and alleviate transplantation-related pressures.<sup>[13]</sup>

## CONCLUSION

The participants in this study equated living with a transplanted heart as "living under the perfect storm of problems." Heart transplantation is associated with different problems such as financial crises, physical and psychological problems, and ineffective role performance. The findings of the present study can be used to improve heart recipients' coping with their transplantation-associated problems. Moreover, the findings provide a holistic view about the outcomes of heart transplantation and can help heart transplantation teams predict the outcomes and adopt strategies to effectively manage them. The limitation of this study is that these findings might not be generalized to the population of heart transplant patients in other cities or contexts. Therefore, further studies on patients living in other cities might be helpful in deeper understanding of outcomes of heart transplantation.

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## Conflicts of interest

There are no conflicts of interest.

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