



## Back on the Road to Life: Iranian Patients' Experience of Heart Transplantation

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### Abstract

**Introduction:** Heart transplantation is a standard treatment for end-stage cardiac disease. In addition to inducing physical changes and improving the quality of life, it causes unique mental and psychological changes in transplant recipients. Therefore, this study sought to explain and interpret the experience of heart transplant recipients in Iran.

**Methods:** Using a qualitative content analysis approach, this study was performed on 13 heart transplant recipients in Tehran. The data were collected through observation and semi-structured interviews. The participants were selected using purposive sampling, and the interviews continued until data saturation. After obtaining informed consent, interviews were recorded, transcribed, and analyzed using conventional and concurrent content analysis.

**Results:** The analysis of the data revealed two stages experienced by heart transplant recipients. The transition stage was categorized into two concepts of "emotional turmoil" and "feeling of duality". The emotional turmoil was subcategorized into feeling guilty, alienation with the new heart, and gratitude. Besides, the "feeling of duality" was subdivided into personality change and lifestyle changes. The stabilization stage was conceptualized into "self-acceptance" which was subcategorized into three concepts of the acceptance of the new heart, feeling of unity with the donor, and normalization.

**Conclusion:** Adaptation to the new heart is a multistage process in heart transplant recipients. Based on the insights from this study, it can be concluded that healthcare professionals need to improve their knowledge of post-transplant changes, recipients' feelings, and their adaptation strategies. They are also advised to address the physical needs and mental concerns of transplant recipients.

**Keywords:** Adaptation, New heart, Heart transplant

### Introduction

Heart transplantation with an average survival rate of five to seven years is the

ultimate treatment for patients with end-stage heart disease (1). Heart transplant surgery seeks to improve heart failure and is

recommended in cases when all other treatment options fail (2). The first human heart transplant was done by Christian Bernard and his team in 1967 (3). The first heart transplant in Iran was performed by Daneshvar in Tabriz (4) and the first successful heart transplant was performed in the same year by Mandegar in Tehran (5). About 5,000 transplants are performed in the world each year and 150 to 200 heart transplants in Iran. Heart transplantation aims to help patients return to normal life, to maximize their quality of life, and to reduce the cost of care (6). Although some heart problems of recipients are resolved by heart transplantation, they face new physical challenges such as the possibility of transplant rejection, infection, renal dysfunction, and psychological problems such as depression, anxiety, and new mental pressures (7).

Recent research on organ transplantation focuses on the three domains of quality of life, adaptive mechanisms, and experiences of transplant recipients and concerns of recipients and their families, obstacles to individual development, and their feelings and emotions have received less attention (8-9). Transplant recipients are prone to numerous physical and psychological problems. Raiesdana et al.'s study on post-transplant challenges revealed three subcategories of stress, physical consequences, and interaction with the donor and the family, implying a challenging life after transplantation (10). The heart as a body organ is symbolically the source of feelings, emotions, and personality. Heart transplantation is an important event in patients' lives that can lead to changes in psychological and social conditions, quality of life, and self-image of the recipient (11). A study by Abbey et al. showed that heart recipients have a constant concern about the

donors and their family and the emotional challenges of accepting the heart (12).

Psychologically, heart transplantation means more than one surgery to patients because before the surgery they are faced with the fact that they are waiting for the death of a person who is a candidate for organ donation due to illness, suicide, or accident, but they are still alive. Therefore, they feel ashamed, agony, and guilty. Moreover, since they know the heart as the center of love, personality, and emotions, they are worried about acquiring their former personality and adopting the donor's characteristics (13). As Kraft et al. suggested, after heart transplantation, the stability and nature of the "self" are constantly impaired (14). Research has shown that patients are concerned about having some of the donor's characteristics and feel "reborn". Even some patients have no sense of ownership over the new organ in their minds and have stated that the transplanted heart is alien to them (10). Since heart transplantation affects the mental and physical conditions of patients and given that patients' mental states affect the transplantation outcome, recovery process, and postoperative complications, nurses can improve patients' mental health and promote their physical conditions by considering the spiritual dimension of care as an effective nursing intervention (15). In the post-transplantation stage, patients use different methods to adjust to the new heart. They face different adaptive functions such as losing their hearts, a spiritual understanding of the new heart, psychological concerns about death and rebirth, the feeling of guilt, and personality change (16). These mental changes affect patients' compliance with the treatment plan and subsequently their morbidity and death (17). Nurses as primary trainers need to be aware of patients' mental changes before and

after heart transplantation so that they can respond appropriately to patients' questions and concerns (9).

Given the increasing number of heart transplants in Iran and the cultural and religious differences among Iranian people, this study was conducted to gain insights into the emotions and attitudes of heart transplant patients towards the donor and how those feelings affected their personality change after surgery. The growing body of qualitative research prevalent in nursing studies is based on the assumption that reality can be interpreted in different ways. Qualitative researchers believe that people can best describe the situations and feelings of their world. In this study, a qualitative research method with a content analysis approach was used to explore the participants' emotions and reveal their experiences.

## Methods

The present study was a qualitative research and employed conventional content analysis. The research population included all heart transplant recipients in Iran and the location of the study was one of the hospitals implementing heart transplantation in Iran. The participants in this study were those who have undergone heart transplantation, were capable of expressing their feelings and emotions without embarrassment or emotion control, and were interested in expressing their experiences. They had to be over 18 years of age, having a heart transplant for at least six months (18), be in good health, and not be at the stage of rejection. The participants were selected using purposive sampling and the sampling procedure continued until the data saturation point where no new data were obtained and the findings were repeated earlier. A total of

16 interviews were conducted with 13 participants. After receiving an introduction letter from the hospital and presenting it to hospital officials, the researcher attended the clinic on the days the heart transplant patients referred there. The researcher introduced herself and provided some explanations about the objectives of the study and the research method. Upon the participant's consent, the researcher attended a place appointed by each participant to interview them. Accordingly, 16 interviews were conducted at the heart transplant clinic, one at the researcher's office, and one at a patient's home. Each participant was interviewed after reading and completing the informed consent form. At the beginning of the interview, the participants were told that their statements would be recorded, transcribed verbatim, and analyzed, and they were allowed to leave the study at any time. The researcher provided her phone number and email address to the participants so that they could contact her if needed. Each interview lasted between 30 and 70 minutes (50 minutes on average). The first 10 minutes of each interview was spent on getting familiar with the participants and explaining the research objectives. Then, upon the participant's permission, the sound recorder was put in a place visible for the participants to record their voice during the interviews. The participants' moods, movements, and behaviors were also observed. At the beginning of the interviews, the participants were asked to talk about their post-transplant life. Then, following the research objectives, some questions were asked to explore the participants' experiences and feelings after transplantation. An interview guide was used that contained some general questions including *What are your experiences with getting a new heart?* Follow-up questions (e.g., *Can you provide*

more explanation? Can you give an example? etc.) were asked to identify the main themes associated with the research topic. The process of data analysis was performed simultaneously with the data collection procedure with a continuous comparison of data according to the steps proposed by Graneheim and Lundman (2004) (19). Initially, the transcript of each interview was read several times. It should be noted that each interview was considered as a unit of analysis. Next, the interview transcripts were reviewed with a focus on identifying semantic units relevant to the purpose of the study. Then, the identified semantic units that were phrases, words, or paragraphs of the participants' expressions were written and summarized on log sheets. Subsequently, the extracted semantic units were classified as abstract concepts in the form of codes and subcategories based on their similarities and differences. In the last step, the main themes of the study were carefully extracted and reported.

Then the researcher and the participants reached a semantic consensus about the identified categories. The four criteria (credibility, dependability, confirmability, and transferability) proposed by Lincoln and Guba (20) were used to ensure the validity of the data. The credibility of the data was checked based on the researcher's

engagement with the research problem and the procedure taken to collect the data. The participants' opinions about the interview transcripts and extracted codes were also used. Besides, the participants were selected from among people with diverse demographic characteristics. To determine the dependability of the data, an external observer familiar with the qualitative research and clinical settings was asked to assess the data and there was consistency between the research procedure and the data. To ensure the confirmability of the data, all activities carried out by the researchers including the data collection and analysis procedures were carefully recorded. Finally, to check the transferability of data, the researcher shared the findings with two patients who did not participate in the study to confirm the findings to be consistent with their experiences.

## Results

A total of 13 heart transplant patients (7 males and 6 females) with a mean age of 40.46 participated in this study. Besides, 9 participants were married, three of whom were married after the transplant (one having a child) and four participants were single. The demographic characteristics of the participants are shown in Table 1.

**Table 1. The participants' demographic characteristics**

Row	Age	Gender	Education	Marital status	Occupation	Transplant duration
1	57	Female	Diploma	Single	Housewife	6
2	26	Male	Diploma	Single	Worker	1
3	32	Female	Bachelor	Single	Housewife	20 months
4	59	Male	Diploma	Married	Retired	8
5	55	Male	Middle school	Married	Retired	6
6	27	Female	Diploma	Married	Housewife	7
7	23	Male	Bachelor	Married	Clergyman	7
8	48	Male	Diploma	Married	Retired	7
9	60	Male	Elementary school	Married	Retired	7
10	37	Female	Elementary school	Single	Housewife	3
11	28	Female	Bachelor	Married	Social worker	11
12	43	Male	Middle school	Married	Driver	2
13	31	Female	Diploma	Married	Housewife	10

The results of the data analysis showed that patients experienced different feelings about the transplanted heart depending on the time

of transplantation. The post-transplant period was divided into two stages: the transition stage and the stability stage (Table 2).

**Table 2. Categories and subcategories identified in the data**

Stages	Main categories	Subcategories
Transition stage	Emotional turmoil	Feeling guilty Alienation with the new heart Gratitude
	Feeling of duality	Personality change Lifestyle change
Stabilization stage	Self-acceptance	Accepting the new heart Feeling of unity with the donor Normalization

**The transition stage**

The transition stage was categorized into two concepts of "emotional turmoil" and "feeling of duality". The emotional turmoil was subcategorized into feeling guilty, alienation with the new heart, and gratitude. Besides, the "feeling of duality" was subdivided into personality change and lifestyle changes.

**Emotional turmoil**

The participants stated that in the first months of transplantation, they had different and transient feelings about the new heart. Although they felt rescued from death and being given a new life by transplanting a new heart, they were faced with new psychological concerns. Many of them felt guilty about receiving another human’s heart and saving their own lives. The participants felt that the donor had died to save their lives and that they had taken possession of his/her heart. In fact, the critical conditions caused by end-stage heart disease were resolved for the patients and they started a new struggle to adapt to the post-transplant situation. At this stage, the patients were faced with new problems. For instance, many patients felt

guilty about receiving another human’s heart and saving their own lives.

Participant 9, a 60-year-old man who underwent heart transplantation seven years ago stated, *"Although doctors told me that the person who gave you his heart was brain dead and never survived, I still was in a bad mood for the first few months. And I always felt guilty. I felt like God had taken his life to bring me back to life. I hated myself"*.

Participant 5, a 31-year-old woman who underwent heart transplantation 10 years ago stated, *"Early on when I was transplanted, I was thinking a lot about Zeinab (the name of the heart donor). I used to say you're alive and I'm dead. One day I was thankful to God for giving me life again, the other day I was upset why someone was dead and I was alive. Sometimes, I talked to her and thanked her. Because I owed her my life"*.

The next theme in this category was the alienation with the new heart. After heart transplantation, participants considered the new heart alien to their body and stated that a new organ had entered their body that was strange to them.

Participant 13, a 31-year-old woman who



underwent heart transplantation 10 years ago said, *"After my transplant, I had a feeling I had never experienced before. I felt like I had known a source of energy for years. I knew it was my body, but I felt like something strange or non-mahram had been added to me. I thought I had two control centers that were in conflict. I was confused and harassed. I felt some kind of duality. I said it might be due to my new heart"*.

Gratitude was the last theme in this category. All participants stated that they felt grateful to God after transplantation for granting them the opportunity to live again. They saw the new heart as the result of God's grace and generosity.

Participant 12, a 43-year-old man who underwent heart transplantation 2 years ago said, *"Early on, after my transplant, my faith in God increased, I became more religious. I always prostrated myself and thanked God; I always said Thank you God! This heart is Your divine gift to me. Because of the new life God has given me, I have tried to reduce some of my wrongdoings. It's as if people become more spiritual"*.

The next subcategory was "feeling of duality" that was subdivided into "personality change" and "lifestyle changes".

Some participants felt a change in their interests, moods and personality after heart transplantation. Some of them, when talking to the donor's family, found that these changes were commensurate with the mood and personality of the donor.

Participant 8, a 37-year-old woman who underwent heart transplantation 3 years ago stated, *"I became calmer and meeker. Before my transplant, when in Tasu'a and Ashura people cried, I could not cry at all. Now, every Ashura in the afternoon, I feel extremely sad and cry a lot. I think because*

*she (the donor) was a religious girl with strong faith in God, I changed so much. Because of her, I became a firm believer in God"*.

In this regard, participant 4, a 28-year-old woman who underwent heart transplantation 20 months ago stated, *"After my surgery, when I got up and found myself, I felt something had happened to me. I felt like I became a different person I had never eaten lettuce and cabbage throughout my whole life. Those days I wanted to eat a bag of lettuce. My favorite color was red, but all of a sudden I liked colors like coral and turquoise"*.

### **The stabilization stage**

This stage included the category of "self-acceptance" which was further subcategorized into three concepts of the acceptance of the new heart, feeling of unity with the donor, and normalization.

Over time, the participants did not have the moods of inner turmoil and conflict anymore and saw the new heart as part of their existence united with them.

Participant 5, a 55-year-old man who underwent heart transplantation 6 years ago said, *"Gradually, my life became normal. I feel like it is a part of me now. It is six years now and I am busy with my kid and my life. As time goes by, it seems as if one is getting used to everything. Time will solve everything; if it doesn't; it at least makes it seem normal. Sometimes I don't even think I'm transplanted"*.

Participant 11, a 28-year-old woman who underwent heart transplantation 11 years ago said, *"I now think this is me. Over time, I felt it is a part of me. Now that it is eleven years, I no longer have those feelings I had before. Not that I forget, but I feel it is my own heart. I always recite Qur'an and Fatiha for*

*her. Her parents are like my own parents. I just became part of their family ".*

The next subcategory resulted from analyzing the interviews was feeling of unity with the donor concerning physical, sexual, and emotional dimensions.

Concerning physical unity, participant 4, a 28-year-old woman who underwent heart transplantation 20 months ago said, "I'm not saying my heart transplantation was a new gift. I say the heart of another person and my body were joined and turned into a new person. Two persons became one who is now sitting in front of you."

Moreover, participant 1, a 57-year-old woman who underwent heart transplantation six years ago said, "Early on when her family saw me they said that our faces looked alike both having white and round faces, her eyes and eyebrows were also black. Her mother told me I was like a sister to her since we looked like each other ".

Concerning sexual unity, some participants admitted that after transplantation, they received sexual characteristics of the donor. In this regard, participant 10, a 37-year-old woman who underwent heart transplantation 3 years ago stated, "Since I was transplanted the heart of a man, I feel stronger and more courageous. I understand boys more. Even my family tell me, as a joke, you behave like boys".

Regarding emotional unity, most participants asserted that after heart transplantation, they made an emotional connection with the heart of the donor, even talked to it about life's problems and difficulties and considered the new heart as part of their emotional existence. In this regard, participant 4, a 28-year-old woman who underwent heart transplantation 20 months ago stated,

*"Maybe you won't believe me! When I get*

*anxious now, I bite my nails and I know that Mary (the donor) had this habit. Actually, I got it from her. But I became one with Mary. I promised to improve her. I told Mary you must become the best. So I work on nail-biting and recite Qur'an instead of her ".*

Regarding normalization, the results revealed that over time, participants resolved their internal conflicts and considered the new heart as a part of their soul and integrated with it.

Participant 3, a 45-year-old man who underwent heart transplantation 10 months ago stated, "Now everything is normal for me and I have no stress or fear or even surprise at changing my feelings or interests. I consider the new heart as a part of my being and I am busy with the issues of daily life and I do not think about it".

## Discussion

Although heart transplantation is a type of treatment that increases life expectancy and quality of life in patients with end-stage heart failure, these patients encounter various experiences and challenges that may affect their quality of life and survival rate after transplantation (21). Before surgery and long after surgery, these patients may suffer from psychological problems in addition to physical problems and drug side effects. The results showed that as time went by, they encountered unique emotional and psychological changes. Although transplantation gives patients a second life, it influences all aspects of their lives. In this study, the transition stage consisted of emotional turmoil and feeling of duality. In this regard, Stolf et al stated in their study that the emotions of the patients after transplantation, including feeling conscience-stricken, guilty or change in body, are unique to each

individual (22). Kuhn et al also showed that heart transplantation is a multistage process and at each stage, individuals have different emotions. Evaluating patients as well as visiting and caring for patients for several years after transplantation are essential for improving patients' conditions (23). Bunzel et al showed that a number of patients attributed a noticeable change in their personality, feelings, and emotions to heart transplantation. Therefore, attention should be paid to changes in the emotions and personality of patients undergoing transplantation (24). Although heart transplantation is a type of treatment that increases life expectancy and quality of life in patients, the recipients experience many psychological changes after heart transplantation. Therefore, in addition to periodic physical examinations, the mental and psychological conditions of the patients also need to be taken into account (25). Pearsall et al also found out in their study that the incidence of recipients' awareness of changes in their personality after heart transplantation is unknown; nevertheless, based on the theory of cellular memory and its implications for organ transplantation, patients undergoing heart transplantation may face changes in food, music and sexual preferences and interests (26). Almgren et al. in their study concluded that patients after heart transplantation face different adaptive functions such as loss of heart, mental perception of the new heart, and psychological concerns about death and rebirth (16). In the present study, the stabilization stage of the heart transplantation was determined by the subcategories of self-acceptance and returning to normal life and it was revealed that over time, patients considered the transplanted heart to be part of their existence and adapted to it. Almgren et al also indicated that some patients undergoing heart

transplantation experience a sense of nonexistence and loss of coherence and need time to adapt to these conditions (16). Heart recipients face numerous post-transplant challenges they may not be prepared for. They can handle many of these problems by relying on God's infinite power. In their study, Raiesdana et al. concluded that relying on God and accepting divine providence would make transplant patients feel calmer. Heart transplant recipients experience a high level of spirituality that helps them overcome post-transplant consequences (27). Bunzel et al also suggested that patients undergoing heart transplantation use different approaches to adapt to the transplanted heart. Adaptation to the heart of the donor requires great power and adequate adaptation skills. Otherwise, it can lead to depression, anxiety, and mental disorders after transplantation (24).

One of the limitations of the study was the difficulty in accessing patients due to the fact that most patients came from surrounding cities and they needed to be visited quickly and return home due to post-transplant health and safety considerations. The researcher was able to gain access to the participants by spending time, arranging appointments with the participants at their convenient time and place, and paying commuting costs.

## Conclusion

This study showed that patients are more likely to undergo numerous physical, mental, and psychological changes after heart transplantation. These changes were conceptualized into two transition and stabilization stages. Based on the insights from this study, healthcare professionals are advised to improve their knowledge about post-transplant changes, recipients' feelings,



and adjustment strategies. An awareness of the patients' feelings and changes helps the caregiver team to see them as a unique client, and effectively address their physical needs, issues and concerns. Such awareness also helps them to provide counseling and training services needed to improve patients' quality of life. Furthermore, considering the changing behavior and habits of some patients after heart transplantation, it is suggested that more research be done on transplantation issues and transferring the donor's characteristics to transplant recipients.

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