

Life experiences in heart transplant recipients

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ABSTRACT

Introduction: Heart transplantation is considered as a golden standard of treatment for advanced heart failure. After - transplantation health of patients is influenced by numerous issues which many of them are unknown to the treatment team including nurses. This research - with the aim of describing the life experiences of heart transplant patients - help us to get close to the patients private life and gain comprehensive and a general understanding of all aspects of their life. **Methods:** This study applied qualitative approach using phenomenology method. The purposive sampling was conducted and continued with 9 participants until information reached saturation point. The participants are the heart transplant recipients who had surgery in Esfahan's Heart Surgery Center of Shahid Chamran. **Results:** The extracted interviews were analyzed through Colaizzi method: The eleven extracted main concepts were included: Belief, tendencies of the recipient and family of donor, bewilderment, moment of facing with transplantation, satisfaction, vital organ, support, temperament, physical effects of transplantation, mental changes, paradox of life and death. **Conclusion:** In heart transplant patients, being in touch with peers and family support have an important role in putting up with the transplantation issue. Lack of social situation and social support were among the patients distresses. Lack of the necessary information about transplantation made patients dissatisfied with the heart transplantation. Regarding the research findings, training received by patients would not be suffice and lack of information has been made them face with problems; therefore, the nurse team of transplantation should play more an active role in training the patients.

Key words: Experience, heart transplantation, phenomenology

INTRODUCTION

The first successful heart transplantation was done by Christian Bernard in 1967. The heart transplantation – in comparison with surgical and medical treatments for advanced heart failure – was chosen as a golden standard

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of treatment since then until now.^[1] However, heart transplantation is faced with numerous challenges and one of the most important of them is lack of donated organ, which has been made the waiting time longer to transplant^[2] and as a result, 20-30% of patients die before can find a donated organ.^[3] Although, the critical conditions – being created for patients with terminal stage of heart failure is solved to a large extent but a new challenge will be begun for adaptation to the after - transplantation conditions and patients will face with new issues and problems; hence that many patients and their families unrealistically expect that all their life problems being solved by doing heart transplantation surgery and patients can return to normal life. But it should be stated that although the heart problems being removed, the new transplantation - related problems including side-effects of medicine, rejection of transplant organ, infection, financial limitation will mostly be appeared.^[4] The studies on patients waited for heart transplantation showed that, in patients' opinion, need for training and information is among the most

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important requirements to face with critical conditions during waiting time for transplantation.^[5] Sadala and Stolf studies on 26 heart transplant recipients showed that, in patients' opinion, living with the donated organ is complicated. After transplantation, patients were happy about their new life and in contrast were dissatisfied with pharmaceutical side-effects and created problems.^[6] Tong *et al.* in an article in 2009 showed that the chance of after-transplantation new life is made people happy but they will face with numerous challenges including fear of death and anxiety in relation to future.^[7] Delbarrio *et al.* study on organ-transplant recipients also showed that knowing these patients experiences helps nurses to gain a comprehensive understanding of their health process and nurses – as the first supplier of medical care-can play the role of protector of organ recipient and liaison along with other member of transplantation team.^[8] Reviewing the life experiences of heart transplant recipients helps to get access to unknown aspects of their life which ignored by nurses and the rest of the care team and have an effect on their health. In this research, we are going to explain the life experiences of heart transplant recipients to help these patients by use of its results.

METHODS

This study applied qualitative approach using phenomenology method to explain the life experiences of heart transplant recipients. The clinical science and professional nursing attention to the holistic care has provided an area for the phenomenology researches. The phenomenology research is derived from an inductive descriptive method and originated in phenomenology philosophy which emphasizes on understanding the nature and essence of the phenomenon. This philosophy not only emphasizes on the understanding of the definite part of human behavior but also its main principle is to understand the total existing responses.^[9] Phenomenology research helps to describe the experiences and phenomenon as they experienced.^[10] Therefore, the aim of phenomenology is not studying the unreal situation, but is studying live experiences, emphasizing on routine stories and giving meaning to the life experiences.

The participants of this research were included 4 men and 5 women who selected with a wide range of age, cultural history and level of education [Table 1]. The patients who took part in

this research had heart transplantation surgery in Esfahan's Heart Surgery Center of SHahid CHamran, those who were interested in this research and voluntarily took part in it to explain their experiences and were conscious and could state their experience and had not experienced any other transplantation. Moreover, the patients who changed their mind to continue or take part in research or those couldn't continue to cooperate due to mental and physical conditions were omitted.

In phenomenology, selecting the participants called sampling and participants should have experiences related to the under-study phenomenon.^[11] The purposive sampling was conducted and data was collected through the deep and no-structure interview until the information reached to saturation point with nine participants.

After asking necessary permission and selecting the participants, they are given the necessary explanation about the research aims and they are gained their oral and conscious consent and were assured that their information would not be revealed. The interviews were carried out in participants' place of residence and they were flexible between 60 and 90 min based on the patience and tolerance of participants. The participants' statements were recorded on the audio file and each interview wrote on the paper word-by-word after repeatedly listening. Base of questions was included to state the participants' experiences since they found themselves in need of heart transplantation until the time of interview. All interviews were carried out by one researcher. The data was analyzed through seven-stage Colaizzi method.^[12] During the first stage, versions of interviews were studied carefully. During the second stage, the important sentences and those related to the under-study phenomenon underlined. During the third stage, the extracted meanings were conceptualized and formulated and initial codes extracted from underlined important sentences, which related to the under-study phenomenon. During the fourth stage, after repeatedly reading and repeating the third stage, the formulated concepts organized in to categories and thematic clusters based on the common meanings. During the fifth stage, the results of each cluster were gathered using comprehensive explanation of the under-study themes and bigger categories formed which were closer to the main concepts resulted from analysis the information. During the sixth stage, concepts resulted from fifth stage were integrated and more general

Table 1: Characteristics of participants of research

Row	Participant	Gender	Age	Duration of transplantation	Education	Job	Marital statuses
1	Number 1	Male	53	14 months	High school diploma	Army retiree	Married
2	Number 2	Male	24	10 months	High school diploma	Photographer	Married
3	Number 3	Female	49	11 months	Fifth grade of primary school	Housewife	Divorcee
4	Number 4	Male	58	8 years	Third grade of primary school	Factory retiree	Married
5	Number 5	Female	35	8 months	High school diploma	Housewife	Divorcee
6	Number 6	Female	49	6 months	First grade of junior high school	Housewife	Married
7	Number 7	Female	58	3 months	Illiterate	Housewife	Married
8	Number 8	Female	54	15 months	Second grade of junior high school	Housewife	Married
9	Number 9	Male	48	1 year	Third grade of primary school	Taxi driver	Married

and abstract concepts formed and main concepts of research created. During the final stage, we referred to the participant one-by-one and asked them about the accuracy of research findings and investigated their confirmation toward extracted subjects.

In this research, In order to increase the accuracy and exactness of data, the participants asked about research questions in a different way so that the possibility of presenting the wrong information being decreased or removed and as a result, the answers became stable. As the method of data collecting was deep-interview, we tried to carry out the interviews carefully and without any fanaticism to get enough information so that if other researcher repeats the same process, he/she can get the same answers. In order to assure of reliability of data analysis, the researcher referred to each participants to ask them whether the comprehensive and final description of findings reflects their experiences or not.

RESULTS

270 initial codes extracted by studying the written interviews and placed in the thematic categories and 27 s level main codes resulted from them. At the last stage, the bigger categories created and eleven main concepts of research formed; those themes and codes represent in Table 1.

Mental changes are among the main concepts of research which is resulted from the second level codes of peace, depression and disappointment. The patients undergone the heart transplantation experienced the feeling of hopelessness along with signs such as seclusion, crying and loss of spirit because the vital importance of heart and feeling the loss of main limb and death. They were tired of numerous problems and great stresses and it seemed that peace was necessary for them after going through cumbersome stages of transplantation.

Participant number 3 stated that:

'... I am not in mood to talk to anybody and cannot tolerate my neighbors and their statements; we already met each other and talked and confabulated but since I got sick, I am not in mood to do something or meet somebody and became taciturn and others have a complaint against my new mood....'

Participant number 7 states about her disappointment:

'... When my trial results are OK, I feel OK too but as smallest changes being made in my trial results, I feel disappointment again; it is not under my control, I tolerate many difficulties but I think that all of them have been useless.

Support is among the main concepts of research which is resulted from integration of supportive sources and economic problems. Lack of social support and lack of social situation are among the important after - transplantation distresses of patients. Patients had experienced existence of supportive

sources including family, treatment team and peers in spite of lack of economic sources and high treatment expense and unemployment. Alternatively, some of the participants did not enjoy family support in this path and pointed out this emptiness.

Participant number 7 has a complaint against the lack of family support and states that:

'... Nobody supports us. We referred to everywhere but everyone represented a different solution but at the end, we had no solution to follow. We, as the heart transplant recipients, have no social situation after transplantation but now I am better than before and can do something by the support of others and be active in the society but without support I can do little...'

Participant number 3 bring up lack of family support:

'... Not only my parents but also my siblings have left me and only my husband was beside me; my family told me that I must not undergo the heart transplantation and should not expect anyone to help; just my husband support me and it was so hard for me not to have a family to support...'

Physical effects of transplantation are among the main concepts of research which are resulted from the second level codes of before - transplantation physical state and after-transplantation physical effects. The participants' experiences of before-transplantation physical states were unpleasant so that remembering and reviewing them was hard and hurtful in some cases. After transplantation, the participants had no complaint against the signs of asthma and heart problems but the most important issue was physical effects resulted from consumption of medicine which made numerous problems and some of them expressed their discomfort about abundance of resulted signs.

Participant number 5 has a complaint against the before-transplantation physical conditions:

'... When I cleaned home, I became breathless and I should sit down to feel OK but, lately, I breathed with difficulties and could not to do anything...'

Participant number 4 has a complaint against creating the kidney failure:

'... At 8 months after transplantation, my legs were swollen so that my shoes were not my size anymore and I was forced to wear slipper; when I observed this sign, I saw the doctor and hospitalized for a month and there I found that my kidneys were failed due to side-effects of the medicine.

Temperament is among the main concepts of research. Before transplantation, most participants had state of anger and aggressiveness and after transplantation, most of them had more calm temperament so that some for them though that it

was due to the young heart of the donor but some of them still had state of anger and aggressiveness after transplantation.

Participant number 1 states that:

‘... Lately I was stubborn and not emotional at all but now, I am a different man and even if I watch a film, I promptly influenced by it and become emotional and cry with film...’

Satisfaction is among the main concepts of research. In participants opinion, living with transplant organ is not a positive experience; most of them are satisfied with their heart because they have not the before-transplantation problems but are relatively satisfied with after-transplantation life due to the lack of ability to have complete independence to do their activities and being dependent on others.

Participant number 8 mentions that:

‘... I liked to undergo heart transplantation and could not wait for that; but now I am not satisfied with it and I wish I had not transplanted because I myself cannot do anything and others do my personal tasks...’

Belief is among the main concepts of research which is resulted from integration of second level codes of performance of religious duties and spiritual dimensions [Table 2]. Believe in God has a considerable role in patients’ experiences so that most of them considered the disease as Divine Examination which should felt proud of it and getting this life stage, they owed to faith in God; however, in some cases, they asked God why me? Moreover; they were occupied with the thought of donor and owed their life to them and tried to express their gratitude by praying.

Participant number 1 has mentioned that:

‘... I got my heart from a young boy, here his picture is; I say praying and Quran for him every morning because I owe my life to him. I can just do something like these and cannot do anything else...’

In this direction, Participant number 2 stated that:

‘... Sometimes I was annoyed so much, I asked God why me... because it was not believable for me, I was young and cheerful, I was not bad man or addict or guilty... Then why I should face with this condition...’

Tendencies of the recipient and family of the donor are among the main concepts of research. The participants of this research tended to be in contact with family of the donor but most of them did not tend to be.

Participant number 1 stated that:

‘... I am 52 years old and heart of 18-year-old young man/woman transplanted in to me. I like to be in contact with his/her family

Table 2: Themes which resulted from codes based on the Colaizzi analysis

Row	Codes	Themes
1	Sense of being grateful Spiritual dimension	Belief
2	Tendencies of recipient and family of donor	Tendencies of recipient and family of donor
3	Anxiety Lack of information before transplantation Lack of people and society’s knowledge about transplantation	Bewilderment
4	First moment of facing with transplantation Waiting Moment of transplantation	Moment of facing with transplantation
5	Satisfaction	Satisfaction
6	Death Eager to survive Death and life dilemma	Paradox of death and life
7	Worth of heart Isolation Sense of dependence Submission to the condition Harsh process of transplantation	Vital organ
8	Economic problems Supportive sources	Support
9	Anger and aggressiveness Kindness	Temperament
10	Before-transplantation physical state After-transplantation physical effects	Physical effects of transplantation
11	Peace Depression Disappointment	Mental changes

but they are dissatisfied with giving the heart of their young to an old man; therefore, they refused to be in contact with me.

Bewilderment is among the main concepts of research which is consisted of sub-concepts of anxiety, lack of knowledge before transplantation and lack of people and society’s knowledge about heart transplantation. The participants had many anxieties related to family, transplantation result and future. They stated that lack of the necessary information about heart transplantation and after-transplantation life are among the main reasons of dissatisfaction with transplantation because they did not know what they will face with; moreover, they were dissatisfied with people’s attitude and their unfamiliarity with the need of heart transplant people which hurt patients’ feeling in some cases.

Participant number 6 mentioned that:

‘... I did not know anything about heart transplantation, I thought that it is a simple surgery and I will become healthy as

before and can do my tasks by myself but it did not happened; if I knew the conditions I would not accept to transplant...'

Participant number 8 speaks about her anxiety and future of transplantation:

'... I had heart transplantation and now I think that whether I survive and how long I survive, what will happen at the end and whether I can walk on my foot or not; I have a dime picture of the future and I do not know what will happen...'

Moment of facing with transplantation is among the main concept of research is included the participants' experiences since a moment they heard that they are in need of heart transplantation until entering into the operation room to receive a heart which consisted of the first moment of facing with transplantation, waiting and moment of transplantation. Most of the participants shocked when they heard that they are in need of heart transplantation and couldn't believe it and experienced the stressful waiting time along with disappointment at finding an organ. It was difficult for the participant to talk about that period and they were pleased with ending that period off.

Participant number 5 stated that:

'... When doctor told me that you are in need of heart transplantation, I answered it is impossible, I am so young to transplant; I could not believe at all that I was really sick and needed the help...'

Participant number 2 mentioned that:

'... I could not feel hopeful that I can find a heart on time because just half of my heart was healthy. However, I had put my name in a waiting list for 6 months that was very so long for me...'

Vital organ is among the main concepts of research which is consisted of sub-concepts such as worth of heart, isolation, sense of dependence, submission to the condition, harsh process of transplantation. Patients tried to tolerate the difficult and exhausting condition and dependence on others to keep the new heart health and safe and accepted the existing conditions and considered the new heart as Divine present and miracle.

Participant number 6 pointed out that:

'... It seems that I am born again, I should begin to live again, everything is new to me and I should get the most of this new beginning...'

Participant number 7 pointed out that:

'... My sister-in-law had a kidney transplant and could do her activities by herself after a month; I thought that I will have the same condition but heart transplantation is different from other transplantation.

Paradox of life and death is among the main concepts of research which is consisted of death, eagerness to survive and death and life dilemma. Tendencies to survive and escaping death are among the participants' experiences. During this stage, thinking about death was inevitable and they were ready to accept risks of transplantation to survive because, during all stages, they were confused with choosing between death and life.

Participant number 8 pointed out that:

'... Human is eager to survive and does everything to survive longer; when there is two choices which one of them is death, it is clear that which one is chosen... of course, life and I chose heart transplantation.

Participant number 5 mentioned that:

'... I went to a path that ended in death so that I had done the necessary measurements to get ready for any incidents...'

DISCUSSION AND CONCLUSION

Findings showed that patients are faced with numerous problems which considerably influence on the care quality in this so sensitive condition. In this direction, Rainer *et al.* study showed that heart transplant recipients experience numerous mental changes which influence on their after-transplantation life quality.^[13] Moreover, amount of mental disorders outbreak is decreased over a few years after heart transplantation and the researches showed that outbreak of depression signs in heart transplant recipients who had transplantation 10 years ago is decreased in comparison with after-transplantation initial years.^[14]

This research showed that the support is given by society, family, treatment team and peers has an important role in improving the mental and physical condition of these patients; so that Canning *et al.* considered the existence of social and interpersonal support to be important in reducing the stresses created after transplantation.^[15] In this direction, findings of other study showed that limitation of role function and disorder in social function were among the issues created after transplantation and made the life quality of participants decrease after transplantation; therefore, the better supportive systems support the heart transplant patients, the better the status of patients' life quality would be.^[7]

In this research, the considerable issue is to improve the temperament of most patients which is the result of transplantation. Although, different studies have not been pointed out the improvement in temperament but most patients but some studies have; In this direction, Doering *et al.* study stated that some patients used ineffective adjustment mechanisms to put up with issues when they were placed in hard condition with numerous stresses; this mechanisms caused the signs such as anger and aggressiveness to be appeared in candidates of heart transplantation and using

effective adjustment mechanisms have had a positive effect on patients' temperament.^[16]

In a study by Grady *et al.* stated in their research that amount of satisfaction of heart transplant recipients after transplantation is one of the dimensions of the life quality^[17] and amount of after-transplantation satisfaction is low which is gone back to lack of information about the after-transplantation state and being unemployed after transplantation. Moreover, the results of White-Williams *et al.*^[18] study on 237 heart transplant recipients indicated that being employed after transplantation is among the important reasons influences on the amount of after-transplantation life satisfaction so that amount of after-transplantation life satisfaction in employed people is more than unemployment people.

The patients owe their new life to one who has given them a new life after his/her death. In this direction, Ross *et al.* came to this result that thinking about the donor of the organ is among the existing stresses in heart transplant recipients. In this research, heart transplant recipients had a feel of appreciation toward the one who has given them a new life to them after his/her death but they got in to stress by thinking and speaking about the donor and this feeling has not been related to the time of transplantation; although, heart transplant recipients tended to be in contact with the family of donor they got in to great stress at the time of contact which this made their contact disrupt.^[19] One of the unpleasant experiences of patients has been a lack of the necessary information about heart transplantation and living with transplant organ because they did not know what issues they will face with and how should manage them and this made their future dime; so that, results of Walden *et al.* research indicated that one of the most main need of patients waited for heart transplantation is to gain simple and understandable information related to disease and how to face with emergency cases and status.^[5]

New heart is so worthy so that patients use different interpretation such as Divine Miracle. Based on Ross *et al.* study, heart transplant recipients consider the after-transplantation life as a new life which can experience it again and some of them interpret the new heart as a miracle of their life and feel that they have turned to anew man by it.^[19] When the patients being placed in death and life dilemma, they chosen to be placed between death and life and were selecting new life in spite of problems were ahead of them. In this direction, the results of Lumby research showed that when the patients were being placed between life and death, all of them gone through the stages to get ready to face with death. Although, they got ready to die they experienced a positive viewpoint toward survival and that was hope which made them choose the life and have heart transplantation.^[20]

The results of this research can be used in an educational, research and clinical field. These results help treatment team including nurses of transplantation team to find out that how heart transplant recipients experience after-transplantation

life, what issues they face with and what are their needs to carry out the necessary measurements base on their needs. One of the most important measurements which can fill the existing emptiness to a large extent is to train and provide patients and their families with training and necessary information related to process of transplantation, care and after-transplantation life. Nurse team of transplantation should play an active role in the field of training the patients; regarding the research findings, training received by patients would not be suffice and lack of information has been made them face with problems. Therefore, preparing the educational brochures which consisted of complete details of side effects and possible problems and necessary precautions and taking care at home would be effective.

Heart transplantation is a very stressful surgery for the patients and their families which would increasingly be succeeded if there were necessary support and training and a skilled treatment team.

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