

The support experience of heart transplant recipients

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Abstract

Introduction: Heart transplantation is an important option for patients with heart failure who are at the final phases and have not responded to other treatments. The process complexity for heart transplantation may strict and severe patients who enjoy inadequate support system and their lifestyle is below the standard after transplantation. This research intended to study the experience of the heart transplant recipients of supportive sources.

Materials & Methods: This study applied a qualitative approach using a descriptive phenomenology method. The purposive sampling was conducted with 9 participants and collected data was analyzed through Colaizzi method.

Results: Four concepts were extracted from data including lack of social support, role of spouse, medical staff support and peers support.

Conclusion: The findings of this study on part of the heart transplant recipients' experience can help to develop the care of these patients and the supportive sources and ultimately provide appropriate area to improve the life and life style of patients.

Keywords: Support, Heart transplantation, Qualitative approach

Introduction

To replace the disabled organs for the human has been arisen in the social-scientific assemblies many before and handled from the scientific, ethical, religious, political and legal dimensions (1). Nowadays, organ transplantation has been turned to a common method approaching to save and improve the human life(2). Organ transplantation consisting from medical experience to main medicinal intervention of selective patients which is clearly right choice for patients who suffer from a final status of organ malfunction. The decisive

aim of an organ transplantation is to improve the life quality for patients with heart, hepatitis and lung disease who are at the final stages (3) and transplantation operation provides the opportunity of the long live helping to overcome the conditions seemed disappointing before this(4).

The conservative treatment is too costly for the patients with terminal stage of heart failure. Although, the surgical operation of an organ transplantation is costly but the role of recent achievements has been turned it -in comparison with the traditional treatments - to the economical treatment(5).

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The heart transplantation is a main medical option for patients who suffer from the heart failure and are at the final phases and have not responded to the other treatments(6) so that the heart transplantation is one of the most vital medicinal dimensions treating the disease decreasing the rate of survival in the patients with progressive heart failure who are at the terminal stage. First heart transplantation was operated in 1967 consequently, it was considered as golden standard in comparison with the surgical and medical treatments for the progressive heart failure in terminal stage of the heart failures (2), imprisonment with the surgical and medical treatments for the progressive heart failure in terminal stage of the heart failure (2).

In order to improve the life quality, caring of organ recipients should consist of physical and mental dimensions along with social dimensions and supportive sources after the transplantation. Given supports to the patients by medical staff especially nurses and patients' family are of imperative special importance. Moreover, having the strong supportive sources after heart transplantation has an effective role in improving the patients' life quality and the rate of survival(4).

In this direction, in a survey stated that from viewpoint of patients, the role of family support and the social support given by other classes of the society such as the supportive associations are necessary and important to fight and pass the path which is full of ups and downs after heart transplantation (7).

In another survey, the heart transplant recipients' believed that relation with the

peers and using their experience for keeping themselves healthy is one of the main requirements after transplantation. Moreover, they also assumed that given supports by religious people is the important supportive sources which effects the experience of this period (8).

The experience of this patients group help the treatment team to distinguish the stressful and effective factors in patients life and intervene to decrease the negative effects on patients health and their disability(9).

Furthermore, patients who succeed having heart transplantation have had specific conditions which could endure the exhausting waiting period and it is very important for the health team to improve their survival and life quality. Therefore, in order to get result from efforts, these patients should be given special consideration. As regards the support is an unknown issue in the life of this patients has not studied before, this research is intended to study the experience of the heart transplant recipients of support.

Materials and Methods

This study applied a qualitative approach using a descriptive phenomenology method. The qualitative research is a medium to gain comprehensive and applied information from the participants and is used in cases that there is little understanding of phenomenon or there is no an appropriate or obvious definition or framework(10). Nowadays, 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 of human(11).

In this research, the statistical universe was consisted of all patients who had heart transplantation and the researcher had access to them. The purposive sampling was conducted by the male and female patients were in different range of age and had heart transplantation at different intervals; they were interested in this research and voluntarily taken part in and were conscious and could state their experience. In addition to, they were omitted from the research in case of any change of mind to cooperate or take part in the research. In this study, without any awareness of participants' quantity, sampling carried out until information reached saturation point and we did not find any new information in the interviews and no code added to the registered codes and no new concept was received too. Subsequently, sampling stopped and the information reached saturation point by 9 interviews as such the number of sample was 9 men.

Data was collected through the deep and no-structure interview. Thus, the no-structure interview started with a general question in the wide range and produced most useful data(11). At first, a general question was asked to start the interview then the interview process was conducted based on the contributor response and the

principal question was assigned in this way "explain your experience about given support to you whilst you were in need of heart transplantation".

In order to analyze the collected data with respect to the consciously satisfaction of participants, all of interviews recorded by the digital recording. Then, the content of interviews immediately wrote on the paper word-by-word after each interview; reviewed, coded and analyzed based on the seven –stages Colaizzi method. During the first step, all Participants' explanation read in order to sympathize with them. At first, the researchers wrote the recorded conversations word –by –word then tried to understand the concepts and depth of statements' by studying them repeatedly. During the second step, the researchers referred to the protocol and underlined the important statements. During the third step, meaning of each important sentence was explained and extended to set the concept. During the fourth step, those concepts were organized as clusters of the contents. During the fifth step; the results were integrated to have the comprehensive description of the under-study phenomenon.

During the sixth step, it was tried that the comprehensive description of the studied phenomenon being distinguished from the statement as much as possible and being stated without any ambiguity.

During the last step, validation was examined through referring to the samples and asking about findings of this step(12). Being justifiable and constant among other features of this study four principals were originated including real value, being applied, stability and being based on reality.

The real value means that the resulted statements of experience were acceptable for the Experienced in the real world and this was verified, in this research, by referring to the participants and confirming the resulted statement.

Being applied or applicability means that do we apply this results for the other places or groups; in this case, the researchers tried to select the participants with wide range of age and cultural history to reach this objects. When the participants gave the same answers to the same question arisen in different frameworks, we realized the stability in research and; also being based on the reality means that research process was without any fanaticism and, during the study, researchers tried to avoid any kind of fanaticism about under-study phenomenon after and before the interview.

Ethical considerations

The researcher asked a necessary permission and letter of introduction and represented them to the hospital in which the study was carried out. The researcher observed the ethical principals' which stated hereunder: the researcher, after asking permission of chairmen, prepared the name and phone

number of the patients and called them. Then, the patients who had more useful information were selected to state the meaning of the experience which is under study; and the different participants were used in order to have useful information and understand the phenomenon. Then, the importance and aims of the research was explained for the participants and they were assured that their privacy would not be revealed. They were also asked permission of taking part in an interview and recording their statements. The participants were assured to have right to quit the research at any time and they are given a copy of research results in order to become aware of the research results.

Results

In general, 9 heart transplant recipients age ranged of 24-58 years old were participated in the research and their demographic specifications presented in Table 1. After analysis the data, the concepts of support from the viewpoint of the heart transplant recipients were emerged as lack of social support, role of spouse and family, treatment staff support and peers support which hereunder discussed.

Table1: Demographics characteristic

Participant	Gender	Age	Duration of transplantation	Education	Job
Number 1	Male	53	14months	High school diploma	Army retiree
Number2	Male	24	10 months	High school diploma	Photographer
Number3	Female	49	11months	Fifth grade of primary school	Housewife
Number4	Male	58	8 years	Third grade of primary school	Factory retiree
Number5	Female	35	8 months	High school diploma	Housewife
Number6	Female	49	6 months	First grade of junior high school	Housewife
Number7	Female	58	3 months	Illiterate	Housewife
Number8	Female	54	15 months	Second grade of junior high school	Housewife
Number9	Male	48	1 year	Third grade of primary school	Taxi driver

Lack of social support

Almost all participants were displeased with the lack of social support and lack of social situation after transplantation. Therefore, this concerns have caused many problems and increased the level of the stress in the patients. The participant number 4 pointed out that “.....the heart transplantation recipients are annoyed and nobody support them .we even have no association to support us and give us a help; no body think about us and we have to do something by ourselves.

The participant number 7 also have complained against lack of social support and stated that “nobody support 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’s by the support of others and be

active in the society but without support I can do little...”

Role of spouse and family

The participants pointed out the importance of the support and role of spouse and family to improve the patients’ health after transplantation. The Participant number7affirmed about the support and the role of spouse so “.....most of my problems are undertaken by my husband and now he manages the life and take care of me by himself and support me for doing every things”.

Alternatively, some families have not supported their patients and they pointed out this emptiness. The participant number 3 brought up the 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 family to support...”

Treatment staff support

The participants of the present study had a positive view about the medical staff support and their sympathy in increasing the stress and coming to terms with the transplantation issue. With respect to that, the participant number 2 states that “....I feared of surgery so much; so when they announced me I decided not to go but the nurses talked to me and their statements relieved me and decreased my fear...”

Peers support

Making friendship with other heart transplant patients and having a conversation with them about the transplantation issue were among the points were implied by patients. Another supportive source pointed by the patients was receiving support from other heart transplant patients and to share their experience which achieved by themselves considerably. The participant number 3 states about the experienced support given by the other transplant patients “...when we see the doctor, we meet each other and most of time we talk about our hearts because we have a common problem and can understand each other better than others.

Discussion

This study is intended to examine the experience of the heart transplant recipients of support. The findings showed that, in general, the supportive sources exist after transplantation have the considerable effect on improvement the patients. The result of

this study showed that the patients were displeased with the lack of society support and the supportive systems after transplantation; and existence of wide social and supportive networks would be worthy especially when the people try to being adapted to the new conditions (13). In discussion of an organ transplantation, the wide social support is the main part of the successful adaptation to stresses after transplantation because the transplantation process, from the examination and waiting for the suitable an organ to the hospitalization and surgery and the period after transplantation, creates extra stress for the patients and their families(14).

The findings of Tong and colleagues study showed that the limitation of the role function and disorder in the social function are among the problems made after the heart transplantation and decrease the life quality of the recipients delete please; therefore, the better supportive systems support the heart transplant patients, the better the status of patients life quality would be(15).

The heart transplant patients have a positive understanding about the interrelationship and their social role after transplantation so that the research findings points out the improvement of the recipients social function after transplantation, in comparison with the before transplantation, which this increases by passing the time and being supported by others (16).

From viewpoint of patients, the family support especially the spouse support has an effective and considerable role to improve them after transplantation. Although, the patients made many problems for their family but they deleted stated that if there

was no family they could not tolerate the hard and exhausting conditions. In this direction, the research findings on heart transplant patients who had transplantation 15 years ago showed that the spouse support has had a positive effect on the survival rate of the heart transplant patients so that the 5-years survival rate for the married patients enjoyed the spouse support and for the single patients or patients with no spouse support has been 84% and 69%, respectively(17).

In this research, some patients lost their family support due to take the risk of the acceptance heart transplantation because family believed this cause and vain expenditure and, from their viewpoint, this surgery absolutely resulted in death. Then they were not willing to spend and finally the patients excluded by them. These conditions placed in intolerance burden on the patients and they must continue to take the responsibility alone. The study of Tang and colleagues showed that 92.2% of the heart transplant patients live with their family and only 62.2% of them enjoy the family support(15). The study of Agren and colleague on the patients waited for the heart transplantation indicates that the lack of family support during the waiting period would postponed the improvement process of patients and make stressful environment for them which causes their conditions grow more critical. Their findings indicates that 30% of the care responsibility of patients who waited for the heart transplantation carried by their relatives especially their spouse and mother so that 75% of who taken care of the patients were patients, mothers and spouses (18).

The support and medical care staff of patients are important issues which have positive effects on decreasing the stress during after and before the surgery operation and the participants also pointed out it too; especially the mental-spiritual support of treatment staff has had an effect in improvement the patients mood. In this direction, the study of Goetzmann and colleagues on experience of the heart transplant recipients showed that the interrelationship of recipients with the treatment care has had an effect on the success of the transplantation and from viewpoint of an organ recipients, the support given by this group is necessary to continue this path(19).

To make friendship and meet other heart transplant patients' obligations a conversation about the existed common issue was developed among the main supportive sources for this patients. Moreover, from their view of points, making friendship with other made them relieved mentally and increased their ability to continue the path. The research findings of the Lin and colleagues on heart transplant recipients indicated this issue and showed that the patients need to know about their peers experience and these can be useful to keep them healthy(8). In this direction, the study of Gangeri on transplant patients showed that meeting and having relationship with their peers help them to adapt to the crises and pass the path (20).

In general, With respect to the results of this study, it can be stated that the support given to this patients become faint after the transplantation, so the lack of support makes the after-transplantation life stressful and

this causes the negative mental and physical effects on patients and consequently, the treatment process and improvement of patients' condition and especially their life quality being overshadowed.

Conclusion

With respect to the resulted findings, it is clear that the supportive sources are important and effective issue to improve patients' status after heart transplantation. Generally, These patients receiving little or nothing social support; and lack of social situation after transplantation and lack of social support are among the patients distresses and the necessity of existence of the social support is clearly felt. In this direction, the politicians' attention is important as such they can help the patients by establishing the Public supports. Although, existence of the supportive systems for each disease is among the main sources to improve the disease but this issue, in discussion of the heart transplantation, seems more impressive because they should pass through the different phases of waiting to find a heart and meet the death issue and spend more money to keep themselves alive.

Having heart transplantation is the start of a so long path and giving support can be one of the key Dimensions to help them; and if there was no multilateral support and the necessary programming, the success rate of heart transplantation would be decreased for the patients and we would not decrease our distance from the worldwide successful statistics. Making friend ship with peers and sharing the personal experience have an important role in coming to term with their disease issue. Moreover, the support is given by family and treatment staff to the patients is necessary and vital in the physical and spiritual improvement. The findings of this study on part of the experience of the heart transplant recipients can help to develop the care of these patients and the supportive sources and ultimately provide appropriate area to improve the life and life style of patients.

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