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Research Article

The Realities of Living With a Transplanted Kidney: A Qualitative Study

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Background: The life with a transplanted organ is different from that before transplantation and is associated with unknown factors. Understanding and acceptance of real experiences as well as training and planning to manage them can reduce stress and anxiety. Because there is no study about it, this study was conducted to explore experiences of these patients.

Objectives: The purpose of this study was to explore realities about living with a transplanted kidney.

Patients and Methods: In this qualitative study, 10 patients with transplanted kidney were selected by purposive sampling from a list of transplant recipients in two referral and specialized hospitals in Mashhad and Ahvaz cities, Iran, in 2014. Data were collected through semistructured interviews and field note, which were analyzed according to content analysis method.

Results: four main categories with 10 subcategories emerged as follows: perception of conditional life (health dependence on the maintenance of the transplanted kidney and continuation of life dependence on the consumption of medications), persistence of problems (necessity of medicine consumption, necessity to follow a dietary regime, transplant rejection, constant stress, necessity to be followed up for treatment, and marriage-related issues), being different (being different from before transplantation and from others), and change in attitude towards life (transplantation as a rebirth and feeling of relief).

Conclusions: The results showed that although transplantation can make a positive change in the lives of patients with chronic kidney disease, it leads to emergence of factors that if understood and correctly addressed, can lead to a realistic look at the new treatment.

Keywords: Expereince; Kidney Transplantation; Life Change Events

1. Background

Due to the increasing rate of chronic kidney disease in Iran, an incidence of 75 patients per million people, kidney transplantation is one of the most important therapeutic methods performed for 49% of patients (1, 2). Accordingly, Iran is known as one of the countries with the most important kidney transplant centers, with 1800 to 1900 transplants per year (3).

Although, kidney transplantation is very effective and efficient treatment, it is not a definitive cure for kidney failure and may lead to potential adverse effects (4, 5). Numerous studies have shown that living with a transplanted kidney can be considered as a chronic disease associated with many challenges, which If the patients understand them and take them as part of their existence, more easily accepts them (6, 7).

Although transplantation brings a person's life closer to the normal state, it is associated with the unknown issues (8, 9). Patients waiting for transplant are afraid of the unknowns of their new life despite the enthusiasm for become a replanted patient (3). Many studies stated that the unknown issues of disease treatment can lead to anxiety in patients; therefore, patients should be familiar with the issues that do not have unrealistic expectations of the circumstances change after new therapy (5-7). On the contrary, studies showed that there was a huge gap between the patient's unrealistic expectations and perception of reality during living with a transplant. Although patients have information on this issue before transplantation, the situation of living with a transplanted organ is different from those before transplantation. It makes them to face the shock of reality when encountering the new situation and its noncompliance with pretreatment dreams (10).

Thus, the transplantation is something more than receiving an organ. Their understanding about the situation and its management can reduce stress and improve self-care behaviors to protect the transplanted organ (11).

Although the largest number of transplanted organs are related to the kidney transplantation, the unknown issues of life after transplantation are still unclear and there is no study about it. Therefore, this study was conducted by qualitative methods that play a more effective

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role in clarifying human's unknown and ambiguous problems.

2. Objectives

The purpose of this study was to explore realities of living with transplanted kidney by using a qualitative approach.

3. Patients and Methods

3.1. Study Design

A qualitative study with a content analysis approach was used to explore the realities of living with transplant. Content analysis is a systematic approach to describe a phenomenon extensively and to create new knowledge on the phenomenal concept for action (12).

3.2. Participants

The participants in study were those with transplanted kidney and were rich informants. Therefore, they were selected by purposive sampling method from the list of transplant recipients of the kidney transplant centers Montaserieh hospital, Mashhad city, and Golestan hospital, Ahvaz, Iran. Accordingly, ten participants were interviewed after the purpose of the study was explained and inform consent was obtained. Inclusion criteria were the minimum age of 18 years, lacking a history of transplant rejection, and elapse of at least two months from the transplantation (Table 1).

3.3. Data Collection

The main method of data collecting was semi-structured interview. The first author performed all the interviews. The main question of the interview was "what problems do you face after transplantation?" After the answers of the participants were received, the interview continued with the probe questions such as "What do you mean? Please ex-

plain more" (13). Data collection continued until data saturation was achieved and no new code emerged. The duration of the interviews ranged from 30 to 100 minutes. Most of the interviews were performed in the hospital or the patient's home. All conversations were tape-recorded and transcribed immediately after the interview.

3.4. Data Analysis

Content analysis method was used for data analysis:

- 1- Transcribing manuscripts: The interview transcripts were entered in the software MAXQDA-10 software (VERBI GmbH, Berlin, Germany. To perceive phenomenon and immerse in the data, the manuscripts were repeatedly read.
- 2- Identifying semantic units: The sentences that referred to part of the phenomenon under study were specified.
- 3- Converting semantic units into open codes: The semantic units were coded to compress the content.
- 4- Checking codes with the text: The codes were regularly reviewed and similar codes were merged.
- 5-Classifying categories: The codes were classified based on similarity and difference.
- 6- Abstracting categories and identifying themes: The categories were compared to get a more general sense of the phenomena under study, by putting the categories together. The formation of abstract categories was aimed at describing the phenomenon (12).

To increase the credibility, member check was done. The codes and categories were sent to the supervisor and adviser who were specialists in the field of qualitative research and were discussed to reach a consensus. Many studies state that analysis process should be fully explained in detail. On this basis, step-by-step analysis process was explained. To facilitate transferability, the researcher presented a comprehensive description of the participants' profile/data collection and analysis processes. Sampling with maximum variance (by age/sex/duration of transplantation) increased the conformability and transferability of data (12).

Table 1. Demographic Characteristic of the Ten Participants With Kidney Transplantation						
Number of Participant	Age, y	Sex	Marital Status	Education	Mean Duration of Dialysis, mo	Mean Duration of Transplant, mo
P1	28	Male	Single	High school graduate	6	10
P2	27	Female	Single	Middle school graduate	18	15
P3	40	Female	Married	Middle school graduate	14	14
P4	39	Male	Married	Graduate University	18	17
P5	30	Male	Married	Middle school graduate	9	31
P6	36	Female	Single	High school graduate	18	120
P7	33	Female	Married	High school graduate	17	36
P8	62	Male	Married	Middle school graduate	13	120
P9	30	Female	Single	High School	2	24
P10	60	Male	Married	graduate	2	120

4. Results

During data analysis, four main categories, ie, perception of conditional life, persistence of problems, being different, and change in attitude towards life, emerged (Box 1). The categories were showed the experiences of Iranian kidney transplant recipients regarding the realities of living after transplantation.

Box 1. Main Themes and Subthemes of Study

Themes and Subthemes

Perception of conditional life

Health dependence on the maintenance of the transplanted kidney

Continuation of life dependence on the consumption of medications

Persistence of problems

Necessity of medicine consumption

Necessity to follow a dietary regime

Transplant rejection: constant stress

Requiring follow-up for ongoing treatment

Being different

Being different from before the disease

Being different from the others

Change in attitude towards life

Transplantation as a rebirth

Feeling of relief

4.1. Perception of Conditional Life

Perception of conditional life is one of the main categories constituting the realities of living with a transplanted kidney. After transplantation, the participants realized that their health and survival depended on the lifelong use of various medications. If they were not consumed, they might go back to dialysis treatment. Therefore, they understood that medications played an important role in their new lives because they preserved the most important aspect of life, i.e. health. If the drugs were not available, they could not easily continue to live like others. In fact, the participants have reached the important point that what was inconvenient in use had become saving their life.

The following field note evokes well the important reality in the lives of transplant recipients, ie, medication-dependent life. During the interview with participant 6, when it was the time to take medication, she asked my permission to stop the interview to take medications. When she took her medication, she showed me the cover and said:

"You can see the medication, it smells so awful. But when I open the medicine, I first smell it a little bit, and then take it, because I know that my survival depends on taking these medications" (P-6).

In fact, the participants believe that their health and survival are not separated from the medication. In this regard, a 39-year-old male participant said:

"Now for us, the transplanted ones, survival depends on the same medication. Our life is not apart from these medications" (P-4).

4.2. Being Different

Being different with two subcategories of "being different from before the disease" and "being different from others" was another theme. It indicates that they understood that they were different from their status before the disease and from healthy people despite the recovery and improvement of the quality of life. They stated that they perceived this important point through being in a new living situation and facing with changes and differences.

A 27-year-old female participant said, "I had already thought that I get as healthy as before with transplantation. However, despite some things that I must observe now, I see that we're not as healthy as before and we cannot say that we are in good health" (P-2). Another participant said, "Now I am no longer the person I was before the illness" (P-6).

Another theme that was frequently used by most of the participants was the fact that "we are different from others" after transplantation. They said that before transplantation, they had the impression that their lives would be just like a healthy person so that they could continue their lives without any restrictions. However, the new situation and some differences in comparison with healthy individuals led them to realize that they were not like a healthy person and necessarily had to follow some restrictions. A 34-year-old female participant said, "In general, if you want to compare yourself with the rest, you can see that your circumstances are different. It is not important for healthy people; they are free to go wherever they want to go and eat whatever they can eat. But, we're not so" (P-3). Another female participant from Ahvaz said, "I differ from other people. They are healthy but I had a transplant. It is true that I had a transplant, but I am defective" (P-9).

4.3. Persistence of Problems

"Persistence of problems" is another category of realities of living with a transplanted kidney. Its sub-categories are "necessity of medicine consumption", "necessity to follow a dietary regime", "transplant rejection": "constant stress", "requiring follow-up for ongoing treatment", and "issues related to marriage". Although the participants reported that after transplantation, they had relieved from dialysis-related problems, it did not mean getting away from all the problems and continuing the life without problem. However, they realized that despite the transplantation, they still faced other problems and challenges. In fact, the participants understood that if they accepted the transplant-associated problems as inseparable realities of living with a transplanted kidney, they could manage them well. Participants acknowledged that some prob-

lems (such as regularly taking medications) were undeniable realities of living with a transplanted kidney from which they could not escape; hence, they had to continue its use to protect the kidney.

"I do not like to take medicine, but when I see that there is no choice; I have to" (P-3). Participant 6, who had kidney transplantation 10 years ago, expresses, "Have you noticed that when water hits a stone, it gives a nice sound. The stone is the same problems around us. After transplantation, there are always the problems with us and we have to live with them".

Important point in the experience of the participant was that she believed that some problems (such as taking medication, following the treatment, and maintaining a dietary regimen) are as a reminder of "having transplanted kidney and trying to keep from losing it". Participants stressed the necessity of following dietary restrictions as a reality of living with a transplant.

They stated that if it was neglected, they had to endure the painful physical complications, in addition to jeopardizing the kidney's health. "After transplantation, I can no longer eat everything. Once I ate a heavy meal, I could not sleep because of colic until morning" (P-2).

Another problem was repeated visits and monthly tests to ensure a healthy kidney. They still had to undergo follow-ups after transplantation. Participant 2 said, "It is difficult to going continually to laboratory and doctor. Hospital and laboratory environments are not durable for me, but they are the facts that exist after transplantation" (P-3).

Fear of "transplant rejection" was another reality of living after transplantation. Despite the pleasant consequences such as freedom from dependence on dialysis, it was a fundamental concern in transplant recipients: "After transplantation, being worried about rejection of transplantation is the major concern" (P-1).

Problems related to marriage are a very oppressive experience, especially for women. However, they turn to trust in divine providence as a fundamental resource for bearing this situation. In this context, a 28-year-old unmarried woman said, "A suitor was supposed to come for me, I told my mom that she must tell them that I had transplanted. Since they did not know this, I was too demanding for them. As soon as we told them my problem, they leave our house as if they seem to escape from a leper" (P-6).

Participant 9, a single woman, said, "For us, as transplanted ones, it has turned into a reality that because of this disease and transplantation, nobody wants to marry us. For this reason, I do not think about this" (P-9).

4.4. Change in Attitude Toward Life

For the participants transplantation means opening a new window to the promising life without crossing the difficulties of dialysis; therefore, releasing from difficulties formed another reality of living with a transplanted kidney. This category is characterized by the fact that not all the realities of living after transplantation are unpleasant. Pleasure of new life is that transplant is a rebirth and

has a different meaning from that of living with dialysis.

Dialysis was a painful event because of changing their beautiful face. It had made them to stay at home, had created living within unwanted limits, had deprived them from attending family celebrations, and had made the continuity of their life dependent to the lifeless machine that its absence was equivalent to death for them. However, transplantation was a beautiful word whose name had brought the smell of life for them, had awakened the spirit of hope in them, had taken them away from annoying physical problems, and had saved them from the deadly clutches of dialysis and its troubles. Perception of "transplantation as a rebirth" could result in care/protective behaviors.

A female participant after 14 months of her transplantation said, "I think God has given life to me again, like a newborn. This good feeling about the transplant causes you to take medication, despite the complications that affect the nerves" (P-3).

Other participants believed that the reality of living with a transplanted kidney sounded like opening wings, getting rid of unwanted barriers of dialysis. Perception of freedom from problems such as painful needles and physical changes was so promising that they accepted the consequent problems. Pleasant reality of transplant was the fact that all participants believed in.

"The fact is that I was saved from dialysis with transplantation. I was on dialysis for almost a year and a half. God is our witness, we were uncomfortable there, we always had to go to the hospital, and we were not able to go to work or travel to other cities; we could not go anywhere else. But now, there is no dialysis-associated problem, as I got rid of it [dialysis], I'm very happy" (P-4).

5. Discussion

The results of present study showed a comprehensive perception of the realities of living with a transplanted kidney: perception of conditional life, persistence of problems, being different, and change in attitude towards life. Conditional life is one of the main categories. Unlike the present study, recipients of bone marrow transplantation in the study by Farsi (14) on the experiences of living with bone marrow transplant did not mention the mentioned theme as a major category of living with transplanted bone marrow because according to the posttransplantation conditions, they stopped immunosuppressive drugs for a short period after transplantation. Therefore, they did not believe that their life depends on taking the medication. However, in kidney transplant recipients, transplant rejection depends mainly on the timely administration of medication. Therefore, they have understood a life contingent on the continuous use of medication as the important fact of their lives. Consistent with the results of the present study, because of the focus on similar stress, others studies argued that medication is an integral part and obligation of life to prevent transplant rejection and kidney health (8).

Being different emerges when these patients compare the current situation with the one before and with the lives of others. Acceptance of these differences resulted in health-promoting and self-care behaviors and adjusted expectations. In fact, in this study, the participants had an upward comparison. They compared themselves with healthy people, in order to find out that current conditions and situation of their lives were different from normal people because the perception of these differences led to focus on the preventive health behaviors. They thought that if they assumed themselves as normal people, they would pass the borders that new conditions had determined for them, and subsequently, they had to wait for painful consequences of crossing these red lines.

Consistent with the results of this study, a qualitative systematic review that was performed on the transplant recipients stated that not gaining normalcy was one of the problems after transplantation (15). However, unlike the results of this study, in a study on the experience of liver transplantation among young people, Taylor pointed out that the participants tended to show themselves normal and avoid to consider themselves as being different from others (16). In fact, it is probably one of the reasons for the different results of the taylor study on young people. To avoid losing their confidence, they did not try to make upward comparison of themselves with their healthy friends. Perhaps it was a downward comparison to evaluate the current situation with the one before transplantation, ie, "being sick", which is a very painful condition. For this reason, they emphasized the word "return to normal state", or "normalcy". In fact, it can be acknowledged that difference in reaching a reality such as "normalcy" or "being different" depends on the type of comparison chosen (upward or downward) in the participants.

Persistence of problems formed another important reality of living with kidney transplant. Single participants raised issues such as marriage problems and the worse situation than that before the disease, while married people stated problems such as fear of childbirth, and men raised concerns such as changes in the employment situation. It was in accordance with the study of Peyrovi et al. on the experiences of patients after heart transplant (17). He also acknowledged that changes in life conditions could save people from pre-illness crises, but it faced them with new challenges and problems. Other studies have also referred to this theme with different terms such as "living with new concerns" and "perception of concerns" (18). They stated that although transplantation leads to a satisfying life, it makes the patient to deal with new concerns that can be different depending on the type of transplant.

All recipients, including heart, liver, and bone marrow recipients, have commonly expressed concerns such as fear of transplant rejection (14, 17, 18). Gill has also pointed out that the stress of transplant rejection accompanies all the recipients (7). Because of approximately 7% to

12% of recipients have transplant rejection within the first year, which increases over time, the fear of transplant rejection is inevitable.

Regarding the persistence of problems associated with treatment follow-up, consistent with the results of our study, Nicholas has also suggested that although transplant has many benefits for the patients, there are challenges such as concerns associated with repeated visits and periodic check-ups in their daily life (19). Following these problems, stresses such as the high cost of medication and the stress of test results should also be addressed. Requirement to observe a dietary regime and tolerance of dietary restrictions were other cases that were included by the participants in the theme of "persistence of problems" as the realities of living with a transplanted kidney. It had not mentioned in other studies related to the transplant (i.e., heart, liver, or bone marrow transplantation) (14, 17, 18). The difference in the perception of the type of problem can be attributed to the difference in the nature of stress and the type of received transplant because kidney transplant is one of the most important ones in which dietary regimen is a significant aspect of care.

The facts of new life were expressed, in addition to unpleasant and exhausting facts, with the words such as "transplantation as a rebirth and feeling of release", which actually led to a change in the patient's attitude towards life as a positive approach. This sense of life again can be seen with different expressions in many studies that have focused on the experiences of living with a transplanted kidney (2, 10, 14). In a study on "the patients' perception of self-management after transplantation", researcher has used the words "freedom" and "release" (5). He stated that although according to the participants posttransplantation life was regarded as facing the new challenges that had to be managed properly, they believed that living with a transplanted kidney was a kind of freedom and release from dialysis, which had trapped them in an unwanted limit. In addition, in another study this change in attitude was presented as "transplant as lifesaving and as a rebirth" because the participants had mentioned the date of transplantation as "their second birthday celebration" (20). The first author of the study, who has the experience of living with a transplant recipient, confirmed the fact that transplant was a rebirth and acknowledged that her brother transplantation day was celebrated by her family as the date of "second birth".

Unlike this positive approach in the present study, which has been confirmed in other studies, kidney transplant recipients in the study of Kamran assumed their life to be death, with lower satisfaction with quality of life because care behaviors were considered as restrictions from their perspective (8). In fact, the negative attitude of the participants to perform preventive cares after transplantation had led them to have such a look at the life.

However, our study participants accepted this new life as a rebirth because they considered the care as a protection, not as a limitation. However, culture, background, and religion of a person could affect this difference in their look at the life because the Muslim participants of this study considered the transplant as a remedy and chance to live again from God.

The results of the study led to improve our perception of the realities of living with a transplant based on the participants' experiences. The results showed that although transplantation can make a positive fundamental change in the lives of these patients, they could also be associated with difficult and challenging problems. Therefore, to select treatment methods for transplantation, patients should be familiar with all the positive and negative aspects of this method so that they do would not experience the shock of reality when they encounter the entirely positive changes after entering into their new life. On the other hand, dialysis nurses who spend a great time with these patients are responsible for teaching the realities and familiarizing patients with the unknowns of transplant. This can be done properly if nurses receive detailed information about the realities of living with the new treatment.

5.1. Ethical Consideration

This study was performed after receiving the approval from the Ethics Committee of university where the researcher was studying (No.: 1392.335). All participants were fully informed of the study objectives. They voluntarily entered into the study without any compulsion and were free to withdraw from the research at any time. They were assured that their names would be confidential. For this reason, numbers were used instead of the names of the participants. The written informed consent was obtained from all participants.

5.2. Limitation

One limitation of the study, which is specific to qualitative research, was that the results could not be generalized due to the nature of sampling. Because this study was performed in the context of Iranian culture, the results can be generalized in this context. Another limitation of this study was the lack of access to the recipients with a transplantation time of less than two months.

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Authors' Contributions

Najmeh Valizadeh Zare: sampling, interviewing and transcribing, analyzing, and writing paper. Easa Mohamadi: study guidance at all stage of the study. Korosh Zarea, Nasrin Ehahi, and Zahra Manzari: study counseling at all stage of the study.

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