

Original Article

The Feelings and Concerns of Patients with Kidney Transplantation In Turkey: A Qualitative Study

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Abstract

Background: Chronic kidney disease is an important health problem that is common in Turkey and the world. The patients with chronic kidney disease are faced with lower quality of life, restricted diets and higher morbidity-mortality rates while waiting for deceased donor kidney transplantation.

Aim: The aim of this study was to analyse difficulties of patients with kidney transplantation and to determine the possible physical, psychological and social problems after transplantation.

Methods: This study is a qualitative study which aims to evaluate their living of the patients with kidney transplantation. Fifteen patients have been included into study who had kidney transplantation in the last six months, who were over 18 years old and had no communication problems between September 2014 and November 2014 at the Cukurova University Faculty of Medicine Balcalı Hospital Nephrology Department Clinical. A deep interview has been made with fifteen patients. The interviews were transcribed verbatim and analysed using thematic analysis.

Results: The mean age of the 15 patients was 21-58 ages, and 73.3% of patients was male. In study, it was seen physical and emotional negativities such as isolation, infection, continuously medicine using and their side effect. Not only had the patients had negative feelings after transplantation, but also more intensive during dialysis period.

Conclusion: Conclusively, nurses should notice the problems seen in individuals following the kidney transplantation and help to describe the necessities of kidney transplanted patients during health care. It has been suggested that nurses should have roles in providing education, consultancy, and motivation to patients with kidney transplantation.

Key words: kidney transplantation, nursing, qualitative study

Introduction

The National Kidney Foundation Kidney Disease Outcome Quality Initiative (K/DOQI) Advisory Board (2002) provides a standard definition for chronic kidney disease (CKD). Patients with CKD should have either a glomerular filtration rate (GFR) less than 60 mL/min/1.73 m² for ≥ 3 months or structural/functional kidney damage with or without changes in GFR (National Kidney Foundation 2002).

CKD is a disease with a high social burden due to the fact that it has an increasing incidence rate, causes high morbidity and mortality rates, and seriously affects quality of life, and renal

replacement therapies needed for its treatment require high costs. The number of patients in this phase in Turkey is more than 40 thousand, and there is an annual average increase rate of 12% (Sengul et. al. 2013, Süleymanlar 2009, Latos 2016).

CKD is currently a global public health issue (Zhang and Rothenbacher 2008). CKD requiring dialysis or kidney transplantation is known as end-stage renal disease (<http://www.emedicine.com/emerg/topic501.htm>). The kidney transplantation can enable patients to have a more normal life than dialysis, and is associated with even better outcomes if it is

performed pre-emptively (Mange and Weir 2003, Meier-Kriesche et. al. 2000, Mange et. al. 2001).

The kidney transplantation is the transfer of a human kidney taken from a living donor or from a cadaver to patients with end-stage renal failure through a surgical method (Habereal et. al. 1996, Hongxia 2006, Muehrer and Becker 2005). The kidney transplantation is defined as rebirth not only for patients but also for their families. While dialysis period is considered a pessimistic, hopeless, desperate waiting period, the fear that the body may reject this new organ which was longingly waited lasts even for long years after transplantation. Similarly, following the acute period problems such as psychosexual concerns and body image concerns appear among patients. Moreover, physiological and psychological acceptance of a new organ, which belongs to someone else, is in question. Psychological acceptance of the new organ by patients and their emotional investments in new object include stages changing from person to person (Latos et. al. 2016).

It is important for nursing and nursing education to understand how people with kidney transplants cope with problems posed by the transplantation and treatment (Polaschek 2003) has outlined a model for the nursing role in the context of renal settings.

In nursing renal patients it is important to develop a relationship between nurse and patient in order to support the person to live as fully as possible. In the current study, people with kidney transplants were compared with an individually matched sample of the Swedish general population (Lindqvist et. al. 2000a, 2000b).

Purpose of the study

It is important for nursing and nursing education to understand how people with kidney transplants cope with problems posed by the transplantation and treatment.

Polaschek (2003) has outlined a model for the nursing role in the context of renal settings. It is important for nursing and nursing education to understand how people with kidney transplants cope with problems posed by the transplantation and treatment.

The aim of this study was to analyse feelings and concerns of patients with kidney transplantation and to determine the possible physical,

psychological and social problems after transplantation.

Methods

Design

This study was performed by using a descriptive, qualitative research method.

Participants and Settings

We included 15 patients with kidney transplantation who were 18 years old or older, who could communicate in Turkish, were well oriented, and volunteered to participate in our study. The data collection was performed until the data started to repeat. The study sample size reached saturation upon the interview with the 10th patient, but we continued to interview with the remaining five patients. The descriptive features of patients are summarized (Table 1).

Ethical considerations

Written permission was obtained from the university hospital (45868485/05-08/01/2015). The aim of the study was explained to patients, and those who agreed to

patients were included in our study. The written consent forms of patients were obtained.

Data Collection

An in-depth interview method was used to collect the data. We used a semi structured interview form, which was prepared in line with the literature (Sampaio de Brito et al. 2015, Sohal et al. 2012, Kalendar et al. 2015, Irving et al. 2012). Interviews were performed in an appropriate room in the clinic with stable patients at Cukurova University Balcalı Hospital Nephrology Outpatient Clinic. The interviews took approximately 30 to 60 minutes and were recorded by obtaining the permission of patients. It was planned to complete the study when the concepts and processes that could answer the study question would start to be repeated according to the obtained data, and/or when there would be no more patients to be interviewed under the current conditions, and the number of patients interviewed at the end of this process reached 15. This number determined the sample size of this study.

Before initiating the interview, each participant was informed about why the interview was to be held, the purpose of the study, rules regarding participation, the freedom to participate in and

withdraw from the study, approximately how long the interview would last and how it would be recorded, and their verbal and written consents were received. After noting demographic information, (Patients' numbers were recorded as P1..... P15 instead of their identity information in accordance with ethical rules), pre-determined questions were asked in sequence. All interviews were recorded by using a tape recorder.

Afterwards, these voice records were put down on paper and a written document of 50 pages in total was obtained. The content analysis was carried out on the document separately for each participant. In this phase, primarily the reviewed texts were read and notes were taken for possible codes and categories. Then, sections of data within the text were coded. The researcher asked another researcher, conducting studies on similar subjects, to code the texts of 5 participants independently in order to ensure reliability and validity, and the codes of both analyses performed for the 5 texts in question were compared, and they were found to be compatible with each other to a great extent.

In our study, we measured empowerment by exploring these questions:

1. What emotions did you feel when you were diagnosed?
2. How did kidney transplantation affect your life?
3. What emotions did you feel concerning dialysis?
4. What emotions did you feel after kidney transplantation?

Data Analysis

We listened to the recorded interviews, transformed them into written form, and applied

content analysis. Data were encoded (open coding) according to the meanings, the related codes were gathered (axial coding), themes were created (selective coding), and the data were interpreted (Streubert Speziale and Rinaldi Carpenter 2007). During the process of reporting findings, various statements of participants were given to show how we classified themes. These statements were kept in their original language as much as possible. The patients' numbers were

indicated in the end of sentences between "()" signs.

Results

The sociodemographic and clinical information of the patients is given in Table 1. Patients participating in the study were between 21-58 years of age and 11 of the patients were male and 4 were female.

Answers of the patients for the question "What did you feel when you were diagnosed?"

In the majority of patients who responded to the question, it was seen that their illnesses met with negative feelings such as sadness, anxiety, psychological depression, fear and future anxiety. However after shock period has been overcome, efforts to cope with the psychological consequences of the kidney disease have emerge with the admission period. Below are the answers given by the patients to this question.

At first I went through a shock. The doctor told me, "You need to undergo dialysis, and you will undergo tonight, immediately." I was devastated at that moment. I said, "What are you saying?" I couldn't believe it. (P1).

Of course you feel emotionally suffocated. I am too young. How can it happen when there is no symptom? I was surprised when it was told I had a problem with kidneys. How can it happen? I thought my life standards would go down. I thought of dialysis as the first thing. I said, "Oh no". There were a few dialysis centres in my workplace. I used to see people who were undergoing dialysis, they were in bad conditions. This is why I was upset about this dialysis issue. (P2).

Actually I didn't care much, probably because I was too young, I didn't know you had to undergo dialysis if you are a real patient, so I didn't care. If I had known, I would have

started the early treatment. My blood pressure was high; I believed that my kidney would have been recovered if my blood pressure had been kept under control. This is lack of knowledge: I feel extreme regret now. Doctors told me I needed to be hospitalized, but I didn't do it. (P3).

Of course, at first I went through a psychological breakdown. I stopped for a moment; in deed, I was unable to bring myself to it. Later on, you slowly get used to it in time. At first I asked myself, "Why me?" but then of course I thought "I am not the only one" and I was grateful to God. So I accepted it. At first, for the first 6-7 months, I went through psychological distress. Every time, I went to see my doctor for an examination, I saw that

my values were getting higher, and of course it makes you upset. (P4).

I was very bored, this disease is not something you can ignore. You may not be able to work, everything can be a problem, like unemployment, lack of money... This is why I was very worried about this disease.

I didn't grasp exactly what was going on. When I was diagnosed, renal failure had not completely started. I just thought there would be changes in my life. We were not informed that I need to undergo dialysis and renal failure cannot be stopped. (P5).

I was psychologically devastated. You can't avoid being psychologically affected when you hear those words. I was affected for 1 year, I used to cry. (P6).

Table 1: Descriptive features of patients

Name-Surname	Gender	Age	Profession	Economical status	Education status	Duration of CKD	Duration of kidney transplantation
S.Ç. (H1)	Male	35 years	Public officer	Fair	High school	4 years	3 mounts
U.K. (H2)	Male	26 years	Tradesman	Good	High school	3 years	3 mounts
E.K. (H3)	Male	28 years	Tradesman	Poor	High school	15 mounts	3 mounts
İ.M. (H4)	Male	28 years	Public officer	Good	College	6 years	4 mounts
N.A. (H5)	Male	29 years	Tradesman	Poor	Primary school	1 year	3 mounts
N.D. (H6)	Female	47 years	Public officer	Fair	High school	9 years	4 mounts
S.A. (H7)	Female	53 years	Housewife	Good	High school	26 years	3 mounts
L.N. (H8)	Female	23 years	Housewife	Poor	High school	7 years	5 mounts
Z.S. (H9)	Female	58 years	Housewife	Fair	Not litarete	7 years	3 mounts
M.G.(H10)	Male	40 years	Retired	Fair	Primary school	4 years	3 mounts
M.S.(H11)	Male	25 years	Tradesman	Poor	Primary school	1 years	35 days
H.T.(H12)	Male	38 years	Public officer	Fair	College	3 mounts	3 mounts
Y.A.(H13)	Male	38 years	Tradesman	Poor	Primary school	19 years	2 mounts
A.H.(H14)	Male	21 years	Unemployed	Fair	Primary school	8 mounts	2 mounts
B.G.(H15)	Male	35 years	Unemployed	Poor	High school	5 years	3 mounts

Answers of the patients for the question “What were your concerns about dialysis?”

It was seen that physical, psychological and social problems have appeared in the patients who started peritoneum and hemodialysis treatment. The most frequent recurring problem was especially tired and exhausted after hemodialysis. The limitation of movement, which can also be described as headache, dizziness and walking, has been the physical complaints of the second time. One of the patients (H7) had the option of transplanting this difficult period without ever living, without dialysis. The patients' feelings during this period were also included in the following interviews. The information about the feelings of patients during this period is given below.

I used to feel very tired, I felt very sick, I was dizzy and I had headaches. They were more often at first, then they started to diminish in time. I sometimes, although not always, used to vomit. All I wanted after dialysis was to go to a room and rest because I was feeling exhausted. (P11).

I used to feel dizziness and exhaustion after dialysis. I adjusted my dialysis times to evening hours, so that I could rest at night. When you are hit on the head with a hard object, you feel weary, it is that kind of dizziness, you feel hazy. Of course I used to get up feeling better after a night's sleep. When you undergo dialysis 3 times a week, you suffer pain every time and you need to lie on the dialysis bed for hours and it drives you into psychological breakdown as well. But you feel the pain, you feel the injections and fistulas. (P12).

I used to go into dialysis for 4 hours, until the noon. I could not recover myself the next morning. After dialysis, I used to rest at home and go to my work. (P13).

I had given up hope on everything before the transplantation. I was dizzy and exhausted during dialysis, I couldn't walk, I couldn't eat what I wanted. Life was very exhausting when I used to go into dialysis. (P14).

My body was all swollen up, I always wanted to stay in bed, I never wanted to leave the house. I was exhausted, I felt

like falling to the ground after walking for 10 metres. Even peritoneal treatment did not help me feel better in the last two years. I could not even bathe myself. (P15).

Answers of the patients for the question “How did kidney transplantation affect your life?”

The patients reported positive and negative feelings to this question. Positive feelings and situations: Freedom, rebirth, perfect affect, good feeling, increase in quality of life, not being dialy-dependent, free speech, young and energetic feeling, happiness, physical relaxation, self-employment, freedom of travel, return to work, increased self-esteem, hope. Negative feelings and situations are mentioned as: masking, social isolation and restriction, fear of organ loss, continuous drug use, drug side effects, disability and early retirement, economic dependence, careful dietary necessity and more focus on health. Below are the answers of the patients to this question.

I couldn't do anything on my own before the transplantation. Now I am able to take care of my own business. I feel better, I feel like I came back to life. I was dead for 6 days in a week, now I came back to life. I didn't have appetite, I couldn't eat anything; now I need to avoid only fatty and salty food, apart from that I can eat whatever I want. (P9).

It is a wonderful feeling, you gather yourself up, you regain your health thank god. Drugs cause some difficulties, for example, they make you feel weary and exhausted. I was more aggressive when I was receiving dialysis treatment, I asked my friends who were also going into dialysis, and they told me it was the same for them. You don't know what to happen, I had my transplantation very recently, so it is a bit uncertainty. I don't know what is going to happen, some time should pass... (P10).

I couldn't eat what I wanted. Everything was limited, I couldn't do anything. But after the transplantation, I am easily able to do these things. I have been told to wear a mask after the transplantation. Now it is forbidden for me to accept visitors, I stay in different rooms with my

family, it is boring to be by myself. I was able to work and take care of myself before I got sick, but after that, I have only been striving to improve my health. After my sickness, I left all those occupations aside, I only strive to improve my health now.(P11).

I received dialysis treatment for three months although the sessions were very short. I suffered lots of problems. I am happy to have got rid of them. It relieves you even to be able to urinate. You feel like you were reborn, it makes you feel like you never lost your health. I am very happy, it is like a brand new page in my life, I considered I have started a new life. (P12).

Answers of the patients for the question “What were your emotional problems after kidney transplantation?”

It contained positive and negative answers of the patients for the question. Positive answers: rejuvenation, especially joy and happiness, and the feeling of opening a new page of life. It has also been mentioned that relief from dialysis, feeling good, psychological relaxation and hope for future business and family building. Negative feelings: It has been expressed that there is feelings of guilt, pity, anxiety and remorse especially about the donor. They reported negative feelings due to lack of self-confidence, feelings of disability, anxiety, feelings of loneliness, uneasiness during control days, fear of returning to dialysis with loss of organs.

This is how a hospital environment makes you feel: it brings tears to my eyes. You wait for a phone call from others, from your family. You feel like crying when your father calls you, for instance. That was a distress I went through, I felt like crying for the smallest reasons. They have been discharged already, why haven't I been discharged? My mother has been discharged 4 days before me, I miss my mother. (P4).

My hands started to shake after the operation. It affects me when I talk too much, I think about the old days or the dialysis days. I think these things trigger this problem. You know what this disease is like only if you personally experienced it. God forbid. I am at ease, my body is at

ease. I want to start working, this is all I can think of. (P5).

It is difficult to adapt to a new life for a patient who recently had transplantation. For example, you feel pain in a joint by chance, I play sports every day, if I feel pain in a muscle, I start worrying, I ask myself, “Oh no, did my potassium level go high?” I am afraid of these things, because I had bad experiences in the past. If your phosphor level is high, it causes very severe bone pain. (P6).

My only concern is that... (crying) my mother donated her kidney to me, so I was afraid something could happen to her. (P7).

Discussion

Transplantation is the treatment of choice for end-stage renal disease; it increases survival and quality of life, while being more cost-effective than dialysis. It is, however, limited by the scarcity of kidneys.

Dialysis period starts after a period that patients are full of negative emotions such as distress, concern, psychological breakdown, future concerns, desperation and fear of death. In addition to negative psychological emotions of patients, they also experience physical problems after haemodialysis such as headache, fatigue and exhaustion. Isolation, family problems, work and future concerns are social problems. In a study conducted by Ozcetin et al., in 2009; it has been reported that haemodialysis treatment makes patient continuously dependent on a machine or the healthcare personnel (Ozcetin 2009).

When patients are offered the chance of transplantation, they feel the happiness and joy and their hopes to get rid of the dialysis obligation and to be free considered the beginning of the post-transplantation phase. The positive emotions and conditions are observed to increase evidently after the transplantation unlike the dialysis period. When the post-transplantation possible risks and obligations are considered as an important handicap, emotions such as anger, disappointment, desperation and pessimism may also be observed. Low educational levels and bad economic conditions may have contributed to these negative emotions.

Cürçani and Tan examined the life qualities of patients who underwent kidney transplantation enhanced and their adherence to treatments increased (Cürçani and Tan 2011). Patients, who previously only experienced negative emotions, not only have an increase in their life qualities but also experience positive emotions and conditions such as feeling free after kidney transplantation, feeling like they were reborn, perfect response, feeling good, increase in life quality, getting rid of being dependent on the machine and dialysis treatment, having an unconstrained diet, feeling young and energetic, happiness, physical relief, being able to take care of themselves, freedom to travel, normal blood pressure values, increase in self-confidence, hopes to start working and building a family, gaining weight for thin patients, and losing weight for overweight patients.

A similar study with donators and donees, and reported that life qualities increased in both groups (Yatkin and Çalışkan 2009). In a cross-sectional study reported that analyse the life qualities and psychological responses of patients before and after the transplantation, physical functions were found to be better in the groups after the transplantation (Sainz-Barriga et. al. 2005). However, patients also report negative emotions and conditions such as using a mask, social isolation and constraints, fear of organ loss, continuous drug use, side effects of medicine, early retirement due to disability, depression, economic dependence, restrictions for sports, heavy exercises and lifting heavy objects. It is understood that social isolation caused by dependence on machines is replaced by isolation arising from infection concerns.

Long hospitalisation, surgical complications, urinary infections, pain and dependence on others are the temporary problems experienced after the transplantation operation. The gratitude felt for the donor continues after being discharged from the hospital and while trying to adapt to normal life and patients at first feel guilt, pity, concern, uneasiness and regret for the donor. In their study, Buldukoglu et al. defined gratitude, fear, guilt and similar emotions (Buldukoglu et. al. 2005). Patients experience negative emotions such as lack of self-confidence, feeling disabled, anxiety, loneliness, uneasiness experienced on follow-up days, fear of organ loss and returning to dialysis, and being reminded of the 'entrusted' organ by the regular use of medicines. Similarly, Frey et.

al reported that patients who underwent kidney transplantation respectively defined five stress sources respectively as "the possibility of being re-hospitalised, possibility of rejection, costs of medical treatment, uncertainty of future and the possibility of infections". Bilateral results have been achieved also in family relations. Positive responses are observed in self-confidence and peace environment.

Gokcay and Cengiz reported that patients received sufficient social support inside and outside of the family and sufficient social support had positive effects on general health conditions and mental health (Gökhan and Cengiz 2009).

Although economic problems or donor-related concerns may seem to be temporary, they negatively affect family relations. Patients suffer from the problems caused by economic dependence arising from job loss, suspension of financial aids, and unemployment. Therefore, it is also reported that patients feel lowly; on the other hand, they do not have any financial difficulty by means of the support of family and close relatives. Transportation and accommodation costs in the period of the transplantation have also been understood to affect negatively the patients with low economic conditions.

Conclusions

Lives of patients who underwent kidney transplantation may be negatively affected due to physical problems, psychological and socio-economic difficulties. Effective nursing care is very important in patients' adherence to treatment and gaining the ability to manage their own lives.

Possible problems and maladjustments can be reduced through effective training before and after transplantation. Despite the physical, psychological, social and economic problems, kidney transplantation patients have increasing life qualities and happiness compared to the dialysis period.

Nevertheless, it is understood that the future-related concerns and the concern of organ loss will be maintained in the next stages of their lives. Therefore, it is beneficial to continue patients' observations and analyses in subsequent periods in terms of nursing care, so that morbidity-mortality rates can be reduced by continuing and enhancing a high life quality.

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