Patients' experiences from their received education about the process of kidney transplant: A qualitative study

Ahmad Ghadami¹, Robaba Memarian², Esa Mohamadi³, Samereh Abdoli⁴

ABSTRACT

Background: Kidney transplant needs long term treatment, care and a follow up. Patients with kidney transplant need support in fields of knowledge, skills and motivations. Several researches showed existing challenges regarding education of these patients. A qualitative study was conducted to define patients' experiences from their received education about the process of kidney transplant.

Materials and Methods: This was a qualitative study with a content analysis approach. Sampling was purposive up to data saturation. The participants aged 18-60 years, had experienced transplantation. The data were collected by semi-structural individual in-depth interviews with 18 participants. The interviews were analyzed by Graneheim and Lundman content analysis method.

Findings: Three general themes of "educational experiences at the beginning of transplantation", "educational experiences in post transplantation care", and "patients' struggle to enhance their awareness in order to preserve their transplanted kidney" were emerged.

Conclusions: The findings showed that patients' did not receive adequate knowledge about kidney transplant process. This issue reveals an unstructured and uncoordinated education given to kidney transplant patients by health team members during kidney transplant process. With regard to high motivation of the patients, designing such educational program based on self-management in the process of kidney transplant for these recipients is essential. Nurses in their educational role can enable the patients through educating them about problem solving methods and selection of the best solution to preserve their transplanted kidney and consider renal transplant recipient self-management as their first priority toward these patients.

Key words: Nursing, qualitative research, education of patients, kidney transplantation, Iran

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INTRODUCTION

ransplantation is a progressive and innovative field of clinical practice. Since the first kidney transplant (KT) was performed between twins in Boston, United States in 1954, expertise and success in this area have grown exponentially. For patients with end stage kidney disease, transplantation is the treatment of choice, offering the opportunity for improved quality of life, free from dialysis.^[1] For most of the patients, kidney transplantation is accompanied with a return to a healthy life with a change in its style. Changes in nutrition and limitation in liquid intake during dialysis period make transplantation very pleasant and joyful for the patients. Longer survival time, lower costs and better quality of life all make kidney transplantation a treatment of choice compared to dialysis among patients with endstage kidney disease.[2-6]

Kidney transplantation needs a lifelong treatment and care together with a follow up. Researchers have reported

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kidney transplantation to need constant care supervision. ^[7-10] In the other words, although kidney transplantation is the treatment of choice for end stage renal disease, it requires lifelong medical treatment and coexisting morbidities are common. In addition to regular medications and transplant center follow-ups, this includes preventing or managing risk factors for cardiovascular disease and cancer, coexistent morbidities or side effects of immunosuppressive therapy, and self-monitoring of rejection and infection signs. ^[11,12] The results of the researches on chronic diseases management have focused on patients' daily life self-management. ^[13] The patients should accept to manage the disease process. ^[14]

Gordon et al. have recently suggested the role of daily life management for transplantation patients as a long-term development and promotion strategy. They have especially stated that involving the patients in dealing with self-management activities is a crucial factor in function of transplantation.^[15]

Renal transplant recipient self-management can be divided into the same components as used for other chronic illness populations: I) management of the medical regimen, 2) management of the emotions and 3) management of the new life roles.^[16] Since KT patients need support in fields of knowledge, skills and motivations,^[17] they should acquire awareness, skills and attitudes as well as adequate resources to attain healthy behaviors in order to feel responsible.^[18]

Previous studies have shown that patients' support through educating them about disease process and needed care to achieve healthiness can facilitate their adherence to diet therapy. [8,14] Education of KT patients is a complicated process including a planned combination of educational activities in order to help them change their behavior in a way that results in their recovery. Molzahn indicates that recipients face new life skills such as checking vital signs, signs and symptoms of the disease, and medication. This is the commitment of professionals to provide healthiness, longer life expectancy through understanding the patients. [19] Numerous studies have indicated the existence of concerns in relation with the education of these patients.

Neyhart has clarified the existing obstacles in education of KT patients: inadequate time for patients' education at the time of discharge; overload of educational materials; communicational obstacles; cultural differences; lack of continuation in education and repetition of the educational concepts; low obedience of the patients in their self-care, and patients' depression. [20] Nurses as

educators, not only are responsible for fulfillment of KT patients' and their families' education but also should pay close attention to their educational needs in the society. KT is a complicated process that needs organized educational programs. Since the ultimate goal of KT patients' education is their adaptation with the imposed changes in their function, just passing information to KT clients is not education, but it is a process including regular and organized steps of investigation, assessment of educational needs, educational programming, educational program administration, and evaluation of educational program.

Evaluation of patients' experiences concerning their received education can reveal existing concerns and the factors influencing KT patients' education in Iran, to conduct appropriate educational strategies with regard to patients' experiences.

MATERIALS AND METHODS

A qualitative study with a content analysis approach to define patients' experiences of their received education about the process of kidney transplantation was conducted in 2009-2010. The research environment was a charity in Isfahan to which KT patients would refer.

The participants were those with experience of KT aged 18-60 years. The sampling was purposive and theoretical (interviewing other participants such as participants' families and charity association members), up to data saturation. The data were collected through semi structured 30-45 minute individual in-depth interviews conducted among the participants and some of their family members. Firstly, some questions were made based on the general goal of the study (e.g. what education have you received during KT process? In addition, explain your educational experiences about KT before, within and after transplantation). Other phrases such as "you meant that", Why? How? When? Who? were also employed. Eighteen participants finally entered the study of whom, three participants were patients' relatives and 15 had undergone KT. In general, 26 interviews were conducted including re-interviews with the participants. A written informed consent (based on Medical Ethical Committee Protocol) was obtained from the participants so that interviews were conducted just with patients' permission. Interviews went on until all codes and categories were completed, and there were no data that needed a new code or development of the existing codes. Interviews were analyzed by Graneheim and Lundman Content Analysis Method.[21] The steps of analysis were as the followings: firstly, each interview was carefully read.

Then, the important education related items were underlined. Next, main existing contexts were coded and the titles of the codes were written at the side of the scripts. Finally, the primary codes were made more inclusive, the themes were classified and ultimately, the results emerged.

Four criteria of dependability, credibility, transferability and Confirmability were employed to increase rigor. In order to ensure the interviews yielded rich and detailed data through participants' experiences, verbatim interviews were reviewed. In order to prevent researcher's experiences influence participants, first the researcher put down his own thoughts about the responses on a piece of paper and tried to avoid these items during the research. The research methodology of this study was clearly explained so that the reader could easily follow up the research process.

The researcher checked dependability of the study through revision and member check. This study has tried to make a background for others' judgment and evaluation with regard to data transferability through clear descriptions.

The researcher tried to preserve all evidences in all research steps in order to prove confirmability. Researcher's interest in the phenomenon under study, his long-term contact with this phenomenon and his struggle to acquire others' opinions in this regard were among other factors to guarantee confirmability. The possible concern in a qualitative research is an early end resulting in attaining an incomplete concept from the situation. With regard to the fact that entrance to research environment in the present study started from Nov 2009 to Nov 2010, the researcher believes to have sufficiently attended the research

environment. Data combination was employed in the present study, and this research had no limitations.

FINDINGS

Mean age of the participants was 37.5 years. The findings concerning marital status, occupation, education level of the participants are presented in table I.

Main core variable of educational experiences at the beginning of KT revealed participants' experiences from their decision to undergo the transplantation. This period includes some events that, based on participants' remarks, formed three sub-themes of insufficient information about the technique of treatment, insufficient information about the process of transplantation and insufficient information about supportive systems. The findings are presented in table 2. The process through which sub-themes were formed is described in details as follows:

At the beginning of KT process, the patients should be given information concerning the treatment. Individuals' experiences indicated participants' insufficient information in this regard. Lack of individuals' awareness about the process of KT was clear in participants' narrations.

The participants stated:

"Unfortunately, contrary to the foreign movies we watch in which nurses explains everything to the patients, it was not the same here. Nobody talked to me, not even the doctor who was there to operate me. He did not come to me to talk about the operation."

"They give us little information, the patient should be

Table 1. Demographic data of participants

Participants	Gender	Age	Marital Status	Duration of dialysis (month)	Duration of kidney transplantation (month)	Education	Job	Preamble
1	Male	36	Married	9	8	Diploma	Driver	
2	Male	28	Single	10	10	Bachelor	Jobless	
3	Female	42	Married	24	15	Diploma	homemaker	
4	Female	28	Single	22	10	Diploma	Secretary	
5	Female	26	Single	12	8	Bachelor	Jobless	
6	Female	47	Married	9	8	Illiterate	homemaker	
7	Male	46	Married	12	7	Primary school	Mosque Servant	
8	Male	33	Married	6	4	Diploma	Real estate agent	
9	Male	41	Married	12	9	Diploma	Bricklayer	
10	Male	64	Married	6	7	Primary school	Retired Army man	
11	Male	34	Married	8	1	Primary school	plumber	
12	Male	41	Married	18	1	Diploma	Self employed	
13	Female	20	Single	7	2	Diploma	Jobless	
14	Female	38	Married	10	8	Bachelor	Homemaker	
15	Male	30	Single	8	6	Diploma	Self employed	
16	Male	30	Married	-	-	Primary school	Brick paver	Spouse M.
17	Female	37	Married	-	-	Diploma	Homemaker	Spouse M.
18	Female	58	Married	-	-	Illiterate	Homemaker	Wife. M

given information and KT process should be explained.

When they refer to hospital or dialysis wards this can be done."

This lack of information about KT puts the patients in doubt and distrust in selection of KT.

Participants stated:

"Well, when I would see my relatives and those with transplantation, I would feel ambivalent and find it risky, what to do when rejected would bugle my mind."

"I was given no information about transplantation."

"If we had been well informed about what to do, how risky it is, and what process we would undergo at the stage of dialysis, we would have looked for transplantation more comfortably, and with less fear." "On the other hand, facing those with unsuccessful transplantation and what we would hear around affect our doubt and make us ambivalence in undergoing this operation."

With regard to this issue, participants said:

"A friend of mine has undergone dialysis for 12 years and again his transplantation was rejected. This impresses me." "In the hospital, I was told, I had to put my back into that since the process was too complicated and needed a lot of energy to follow up. So, I was a little scared there."

The participants had no idea about related associations or supportive organization concerning KT.

A participant said:

"Many people do not know about the charities, I myself did not know the charities until three years ago when I learned about by one of my friends."

Educational experiences in postoperative care of KT:

The theme of educational experiences in postoperative care of KT expressed participants' experiences of KT and the new life they started after KT. The patient starts his/her new life with a transplanted kidney after transplantation. These individuals, through their rest of life, should make a change in their life style and accept new roles in their daily life based on the information given to them by preoperative care team, and at the time of discharge. Immunosuppressive medication is a part of treatment to prevent rejection. Informing the patients about the intake of these medications, needed care and prevention of their side effects by the caring team is essential. This period is accompanied by the events that formed sub themes of insufficient information about necessary postoperative care and insufficient information about medications and their side effects. These subthemes are described in details in the following:

Individuals' educational experiences on how to take medications, related care and side effects prevention were formed from data analysis. The findings showed individuals' insufficient information about the above issues.

Most of the participants stated:

"We were never ever informed about the side effects of

Table 2. Main themes, sub-themes and categories of patients' experiences concerning their received education about kidney transplantation process

Themes	Sub- themes	Categories
Educational experiences at the beginning of transplantation	Insufficient information about treatment Insufficient information about transplantation Insufficient information about supportive systems	Lack of awareness about transplantation, doubt and ambivalence in transplantation, fear of transplantation, lack of information about organization and supportive associations
Educational experiences post transplantation	Insufficient information about post-operative care Insufficient information about medications and their complications	Insufficient information about transplantation medication, insufficient information about necessary care in prevention of medication side effects, insufficient information about signs and symptoms of intention, insufficient information about postoperative care, insufficient information about supportive resources in emergency situations
Personal struggle to increase awareness to reach self- management and transplanted kidney preservation	Postoperative stresses and concerns Struggle to preserve transplanted kidney Struggle to increase awareness Struggle to have self-management in trend of life	Causing side effects, fear of rejection, use of available resources in form of communicating with transplanted patients, making use of obtained experiences, communication with physicians, use of books and internet, discharge education, caring principles obedience, importance of periodical visits and obstacles, accessing self-management in life, changing life style

medication, my eyes got weak about 8 months ago, I told a doctor, I was transplanted. He said, "What a chance you referred to my office. Intake of the corticosteroids results in cataract. How don't you know that? Nobody told you that! You should be checked up by a physician.", "I took corticosteroids after KT, and had a big appetite... I gained a lot of weight, from 54kg to 70kg just in 20-25 days. I used to eat five times form lunch to diner.", "It was all for corticosteroids and I did not know, nobody told me. I was starving and would never be sated."

On the other hand, some of patients' experiences about recovery had been wrongly interpreted by them indicating their lack of sufficient information about the medication side effect on function of different organs in body.

A participant said:

"I thought it was good to gain weight, I thought I was getting healthier, I thought it was normal to have a big appetite as my body needed that, so, I had to eat a lot...."

Some of the patients did not get the answer to their questions concerning immunosuppressive medications side effect due to not receiving sufficient information.

A participant said:

"I used to wear disposable masks because of aphthous ulcer, just after transplantation, I had a lot of oral aphthous ulcers. Wearing mask too much is not good, despite oral hygiene, mouthwash and brushing my teeth, I had yet aphthae. I don't know if it was because of medication, nutrition or the mask I used to wear."

"I do not know the signs of rejection, I think the sign of infection is a fever, this is what I know."

Some participants had not received any information about postoperative transplantation care and had no idea about supportive emergency resources.

A participant said:

"A package of care is needed after transplantation. For example, nobody guided me. My operation overlapped new-year holidays, when all doctors were on vacation. I even did not know how to take my medication, what time to take, my intake time was wrong."

Personal struggle to enhance awareness:

The theme of personal struggle to enhance awareness to

access self- management and transplanted kidney preservation was emerged from 4 subthemes formed by participants' experiences in the received education. The formed subthemes were stresses, postoperative concern, and struggle to enhance awareness, struggle to preserve transplanted kidney and self- management in life that are explained in details in the following. Participants had various stresses and concerns about their transplanted kidney, mainly about rejection.

A participant states his fear of transplant rejection in the following phrase:

"Even now, I have the stress of rejection due to the hard time I had at the time of dialysis. I am scared to return to that bad time. I frequently pray to remain healthy, God forbidden, not to have rejection."

Other participants narrate that:

"In earlier time, I had heard that it is rejected after two years, or a women's kidney was rejected after 40 days, these would scare me. I have a fear of rejection in my mind, I accept everything God wants."

Participants indicated other causes inducing stress and concerns in their life with transplanted kidney as facing medication side effects such as malignancy, dermal lesions, osteoporosis etc. They explained their insufficiency of information about side effects of transplantation related medication and the related care to prevent them as:

"They did not tell as anything about medication side effects... now I have infectious pimples, sure because of side effects."

Other participant says:

"My face skin is ruined, taking CellCept, Sandimmune and Cortone has dermal complications. My skin is now brown with stains, nobody recommend us to use sunlight protection creams under sunshine, they did not recommend me and now my skin is ruined."

Participants started a struggle to enhance their awareness concerning caring principles through communicating with other KT patients and using their own experiences and other available resources. Patients' experiences reveal that the most important resource to obtain information for KT patients is firstly, other KT patients, secondly their own experiences and finally, physicians and nurses. In addition, some studied books and referred to internet.

"First of all, KT patients told us these issues. I personally get these experiences from the patients. Others should do so; we get a lot of information from other patients like which doctor visits you? Which laboratory do you have your tests? What medication do you take?"

"We got these from our transplanted friends, like drink milk with your medication, or don't eat some fruits with them. Some also search the web."

Some participants talked about discharge educations given to them through two pieces of paper.

They said:

"... well, two hours before discharge, the nurse gave me two pieces of paper containing some issues, and explained that... in Tehran, the nurses had given them recommendations."

"They gave us a list of medications and their intake time."

Participants emphasized on a need for holding educational classes and provision of booklets about postoperative essential care.

A participant said:

"... These are all because nobody told me. If they held a class, it would be nice.... We got these through our transplanted friends."

"Some got it through internet. That would be good, if they gave us a guideline or a booklet."

Participants' experiences on postoperative periodic visits reveal the importance of paying more attention to the educational aspect, and appropriate communication of physicians.

They say:

"... Even now, doctors do not pay so much attention. It has got repetitive, it is not educational, they do not do anything special for me."

"Nowadays, I rarely go to visit a doctor, just if my tests show a problem."

On the other hand, some participants pointed to appropriate support and communication of the physicians.

One participant said:

"... I would go to a female doctor every other week. As she had given me her cell phone number, I could call her in case of any problem."

Meanwhile, the participants had concluded that they themselves had to struggle to preserve their transplanted kidney. They struggled through attaining and increasing caring information through accessible resources, life management and making a change in their life style to preserve their transplanted kidney.

A participant said:

"... I tell myself, it is not worth at all losing the kidney, I got with a lot of suffers, due to irresponsibility. I cannot undergo dialysis anymore."

Other one said:

"I follow caring issues a hundred percent, I preserve my transplanted kidney in any way, I try to do my best and the rest is by God."

Participants made changes in their life style to preserve their transplanted kidney and were obedient.

One participant said:

"... Transplantation has not made any working limitations. Just it needs a series of health care. For instance, I never went to swimming pool after transplantation. I knew it by myself that the pool is dirty. Instead, I go for hiking and walking. When it is windy, I wear a mask. I try to wash my hands 20 times a day. If a customer shakes hand with me, I immediately wash my hands."

The participants overcame the problems occurred in their life by self-management.

They said:

"This is the series of actions a transplanted individual should do, like a soldier, have you done military service? I should do that if I want to keep healthy, it is just like military system."

"I do my washes myself, my wife washes the clothes in washing machine, she does the laundry separately as I have to learn, I learn to do, I always do."

"... and even educate you how to check your fever, I learned how to check my blood pressure and even my blood sugar. I can check my blood tests results, as I know what test result can be a problem. All of the transplanted patients know these things, they know about tests."

DISCUSSION

With regard to the findings, patients' education concerning kidney transplantation had no standard educational structure and regularity. Based on patients' experiences from received education in this study, the patients followed self-management from transplantation to preservation of their transplanted kidney and struggle to reach self-management in their new life with a transplanted kidney, and to preserve that.

In this way, they demand for efficient education up to achieve the level of decision-making and problem solving before their kidney was rejected. On the other hand, the findings showed the participants had not received adequate information about the selection of treatment method of transplantation. Education on kidney transplantation can be effective on decision making and making a better perception of transplantation process. Expression of the risks and benefits of transplantation clears the way of transplantation selection. [22]

Numerous studies have reported the feelings of fear, doubt and negative attitude transplantation due to a lack of information or attaining wrong information about KT.[23-25] In a study conducted by Zimmerman, 56% of the participants stated that they had not received adequate information. The patients who were more knowledgeable about transplantation have more positive attitude toward it.[26] Patients should receive understandable information about primary evaluation method, surgery and the stage of returning to life. The recipients should especially have a lifelong respect to responsibilities like periodical visits to the doctor and having regular laboratory tests, management of a complicated diet, immunosuppressive medications, transplanted organ function and liquid intake, checking vital signs, signs and symptoms, playing sport and having a low salt and cholesterol diet. Perception and acceptance of these responsibilities are crucial to guarantee the success in transplantation.[27]

Acceptance of a sophisticated self-care diet is essential and accessory for KT patients. Researches have shown that supporting patients through education process and its needed care to preserve patients' health can well promote their acceptance of diet therapy.^[28]

Having an educational timetable and understandable and clear education are important and the patients should be encouraged to enter this stage willingly. In fact, ideal education as a dynamic, stable, clear and realistic process should start from the stage of preoperative assessment. Participants' stated their struggle to increase awareness in order to access self-management and preservation of their transplanted kidney. Lorig and Holman has suggested five basic skills in recipients' self-management: getting help from supportive centers and available resources in administration of the process related to problem solving, decision-making, formation of health providers-clients cooperation, and performance of programmed activities.[29] Whereas, experiences of KT patients in the present study revealed that the participants themselves struggled to preserve their appropriate decision-making and problem solving ways.

Researches and experimental evidences support the importance of self-management skill in order to attain appropriate clinical results. [30-32] Self-management is essential in success of KT patients as they should manage their health through checking their medication intake and communication with transplantation team.

Encouragement of self-management is a part of patients' education for the recipients. Self-management and its education to patients are directed toward a lifelong change in patients' behavior. [33,34] The patients are taught special skills in this framework which include problem solving, decision making, resources usage, formation of patients' participation, provision of care, and scheduling their activity, their life and self-management. [29] The important point in the study was patients' positive attitude in achieving information in order to live with their transplanted kidney independently for which the nurses, through their educational role and by help of self-management based education, can support the patients and their families in the process of kidney transplantation.

CONCLUSION

Investigation of KT patients' experiences from received education in transplantation process showed that patients had not been given sufficient information. This issue indicates performance of unstructured and uncoordinated education by health team for transplanted patients in the process of KT resulting in obstacles in process of patients' care. Therefore, with regard to high motivation of KT patients in attaining self-care management to preserve their transplanted kidney, achieving its appropriate outcomes, reduction of imposed costs to the patients and health care system of the country due to

rejection, the necessity of a revision in formation of educational committees and designing self-management oriented education in KT process for transplantation candidates and transplanted patients is clear.

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