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The need for renovating patient education in kidney transplantation: A qualitative study

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Abstract:

BACKGROUND: Many kidney transplant recipients lack the knowledge, abilities, and support they need for self-care. On the other hand, most kidney transplant centers do not have a well-planned and specific training program for them, and educational interventions for kidney transplant recipients have not been adequately effective. This study aimed to describe strategies for improving patient education in kidney transplantation.

MATERIALS AND METHODS: Data were collected through semi-structured individual and group interviews with 24 patients, family members, and health-care staff in one of the main kidney transplant centers in Tehran. Participants were selected purposefully, and qualitative content analysis was used to analyze the data.

RESULTS: The main finding emerged from the data was the shift from current patient education program to patient- and family-centered education (PFCE). The strategies to achieve this goal were categorized into four main categories including “continuous patient and family education” (pre- and posttransplant patient education), “facilitating the process” (using new technologies, teamwork education, and patient and family accessibility), “strengthening human resources” (empowerment health-care team, allocation of human resources, promoting staffs’ motivation, and updating educational content and materials), and “monitoring and evaluation” (correcting patient education recording, supervising the patient education, and appropriate educational evaluation).

CONCLUSIONS: Transforming from the current patient education program to PFCE seems to be essential to increase the effectiveness of patient education in kidney transplant process. To this end, providing continuous patient and family education, facilitating the processes, strengthening human resources, and monitoring and evaluation in health-care organizations conducting the kidney transplantation is necessary.

Keywords:

Kidney transplantation, patient education, qualitative study, strategies

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Introduction

Kidney transplant as the treatment of choice has led to better life expectancy, improves the quality of life, and reduces the cost of treatment in patients with end-stage renal disease.^[1-3] After kidney transplantation, patients enter a new pathway in their life,^[4] requiring extensive adaptation and changes in lifestyle.^[5] Successful kidney transplantation will restore health and

improve the quality of life and patient satisfaction.^[6] However, it may cause new challenges including self-care, medication adherence, graft rejection, and infection.^[7] A systematic review revealed that 36%–55% of kidney recipients are nonadherent.^[8] As well as, about 36%–45% of them experience first infections within 3 years following kidney transplant.^[9] Many kidney recipients lack the knowledge, motivation, ability, and support needed for self-care.^[10-13] In addition, the physical and psychological conditions of kidney recipients may inhibit

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learning and using their acquired knowledge in practice.^[14] Patient education has a significant impact on treatment compliance following kidney transplantation by altering the health-care behaviors.^[7,15] While most kidney transplant centers do not have a well-planned and specific educational program for applicants and people living with kidney transplantation^[11] and many educational interventions implemented for transplant patients have not been effective,^[16] this study was conducted to describe strategies for improving patient education in kidney transplantation.

Materials and Methods

This qualitative study is a part of an action research and aimed to improve patient education in kidney transplantation in one of the main kidney transplant centers in Tehran. Purposeful sampling with maximum variation was used to select participants. The inclusion criteria for patients and family members were speaking in Persian, they or their family members recently undergoing a kidney transplant and willingness to participate in the study. The inclusion criteria for health-care providers were having at least 1-year work experience in kidney transplant and willingness to participate in the study. Semi-structured, face-to-face individual interviews conducted with 14 participants (3 patients, 7 staff nurses, 1 physician, 1 nutritionist, and 2 supervisors). To enrich the data by group interaction,^[17] two focus group interviews were carried out, one with 5 participants (1 head nurse and 4 staff nurses) and the other with 5 family members (main caregiver). All interviews were conducted by one of the authors in a private room in the kidney transplant ward. The purpose of interviews was explained to the participants, and then, written and verbal consent was obtained from them for audio recording. At the beginning, a general question, "What do you think about patient education in kidney transplantation?" was asked by the interviewer, and additional and probing questions, depending on the participants' answers, were asked during the interviews such as: "What are the facilitators and inhibitors of patient education in kidney transplantation?," "Can you explain more?," "What do you mean?," and "What do you think?." Interviews were continued until no new data were identified (data saturation). Consent for additional contact was obtained from the participants to confirm their statements and to conduct further interviews if needed. The average length for the individual interviews was 30 min, and focus group interview lasted 42–65 min. Some notes were also taken during the interviews. Notes and audio recordings were transcribed verbatim after each interview and coded with letters and numbers that indicated the order of the interview and analyzed using conventional content analysis method based on the model presented by Zhang and Wildemuth.^[18] The content analysis method is used

to investigate the existence of specific words and concepts in the texts, and data reduction is used to give them structure and order.^[19] In the conventional approach, the use of predefined categories is avoided, allowing to emerge from the data.^[20] Thus, the text of the interviews was read several times to obtain a general understanding of the statements. Coding was done by selecting semantic units, and each interview was considered as the unit of analysis.^[19] Categories with similar codes were created from the first interview, and later, the codes of each interview were compared with each other and with the codes of other interviews. Then, they were placed in a specific category, and this process continued until the final stages of the study. Interviews with other participants and coding of the texts were continued, and partial codes were grouped into the more general topics.^[18] The MAXQDA-2010 software developed by VERBI Software GmbH in Berlin, Germany, was used to organize the data. Guba and Lincoln criteria were used to ensure the trustworthiness of the data.^[21] To increase the reliability of the data, different methods of data collection, protracted involvement with the participants during 12 months (March 2018 to February 2019), and data triangulation (patient, family member, nurse, physician, nutritionist, and nursing supervisor) were used. After the initial coding, the transcript of interviews was returned to the participants in order to ensure theoretical agreement between them and the researcher. Moreover, the transcript of the interviews and coding process was reviewed by the coresearcher, which resulted in approximately 85% agreement.

Results

Participant characteristics are presented in Table 1. After analyzing the data, 520 primary codes were obtained. The main finding emerged from the data was renovating the current patient education program to patient- and family-centered education (PFCE) [Table 2]. The main categories are described as follows.

Patient- and family-centered education

The majority of participants pointed to the importance of patient characteristics and family circumstances in patient/family education as a key element in delivering effective education. They emphasized the need to educate family members (main caregivers) along with patient. "(Education) is the same and everybody gets the same kind of education. I've seen myself doing the same thing over and over again. There are many things that we are just repeating for all age groups. I mean we should have different training for each age group" (Staff nurse N3). Another participant stated: "Look, transplantation is not just one person's transplant. After transplant and discharge, the patients spend almost all their time with their families and have to interact with

Table 1: Characteristics of the study participants

Variable	Classification	Frequency (%)
Kidney recipients (n=3)		
Age	28-30	1 (33.3)
	30-34	1 (33.3)
	34-36	1 (33.3)
Gender	Female	1 (33.3)
	Male	2 (66.9)
Transplant time (years)	0-1	2 (66.9)
	1-2	1 (33.3)
Education level	Diploma	1 (33.3)
	BSc	1 (33.3)
	MSc	1 (33.3)
Family members (main care giver) (n=5)		
Age	30-35	1 (20)
	36-40	2 (40)
	41-45	2 (40)
Gender	Female	3 (60)
	Male	2 (40)
Education level	Diploma	2 (40)
	BSc	2 (40)
	MSc	1 (20)
Health-care providers (n=16)		
Age	32-38	5 (31)
	39-44	6 (37)
	45-50	3 (19)
	52-58	2 (13)
Gender	Female	11 (69)
	Male	5 (31)
Education level	BSc	12 (75)
	MSc	3 (19)
	MD	1 (6)
Work experience (years)	1-7	1 (6)
	8-14	3 (19)
	15-21	8 (50)
	22-28	4 (25)
Status	Nurse	12 (75)
	Supervisor	2 (13)
	Physician	1 (6)
	Nutritionist	1 (6)

them. The family should be well educated on how to interact with the patient” (Staff nurse N7). Another participant noted “I wish they could educate us along with the patient. Almost all care after the kidney transplant is up to us and many of the symptoms and complications are of concern to us. Sometimes we really don’t know what to do” (family member FM1). PFCE can be achieved through the provision of continuous education, facilitating the process, strengthening human resources and monitoring and evaluation.

Continuous patient and family education

Pretransplant patient education

From the participants’ point of view, patient/family education in the kidney transplant process is effective

when it provided in continuous manner, starting in pretransplant phase and continues after the kidney transplant. In other words, its necessary patient/family education starts since renal failure diagnosis, and the patient and his/her family are informed of the disease prognosis. “I think the best time to start education is when the patients are diagnosed with kidney failure and they have not reached the dialysis stage yet. That time, we should talk to patient and his/her family and explain all the alternative treatments and even help patients to see these treatments, so they can make an informed decision” (Nephrologist physician PH 1).

Posttransplant patient education

These trainings should also be continued during the decision to undergo kidney transplant through providing educational counseling along with other medical consultations and reinforce during the inpatient and postdischarge period. “Continuous education means to educate patient before admission, during hospitalization, and even after discharge. Well, I said the training first should be continuous, which means it should never be interrupted” (Staff nurse N5).

Some participants believed in the posttransplant phase, all education should be tailored to the needs of the patient and his/her family and be provided concurrent to them. Furthermore, in order to provide coherent training, clinical guidelines for patient education during and after discharge should be developed. “Everyone transfer his or her own knowledge to patient and somehow everyone deliver his or her own style of education. Maybe my advice is different from my other colleagues so we must have a written guide in this field” (Staff nurse N8).

Facilitating the process

Another strategy outlined by participants for moving from the current patient education program to PFCE was to facilitate processes by employing new technology, teamwork education, and providing patient and family access to the accommodation.

Using new technologies

Due to the ever-expanding technology and increasing access to it, technological tools such as websites, mobile phone, and social networks can be used to provide patient/family education. “We’re living in an era where the internet or virtual networks are really helping. Our young generation or even middle-aged people who know how to use cyberspace or social networks to learn about medications, complications, etc. are easier to train” (Staff nurse N10).

Teamwork education

As noted by the participants, the involvement of different members of the health-care team to provide

Table 2: Strategies of improving patient education in kidney transplantation

Main category: Patient -and family-centered education (PFCE)			
Strategies	Category	Sub category	
Continuous patient and family education	Pretransplant patient education	Starting patient education since renal failure diagnosis	
		Developing pretransplant educational material	
		Providing educational counseling along with pretransplant medical counseling	
	Posttransplant patient education	Individualized patient and family education	
		Concurrent patient and family education	
		Developing patient and family education guideline	
Facilitating the process	Using new technologies	Developing postdischarge/follow-up guideline	
		Web-based patient education	
		Mobile phone-based education and counseling	
	Teamwork education	Using social networks	
		Inter-professional teamwork patient education	
		Using peer-facilitated patient education	
Strengthening human resources	Patient and family accessibility	Providing accommodation facilities for patient and family	
		Providing family member break room in hospital	
		Holding patient education workshops	
	Empowerment health-care team	Providing educational content for health-care staff	
		Allocation of human resources	Designating a patient education nurse
		Designating a follow-up nurse	
Monitoring and evaluation	Promoting staffs' motivation	Using motivational methods	
		Promoting patient education culture	
		Revising the existing patient education contents	
	Updating educational content and materials	Developing the required patient education contents	
		Correcting patient education recording	Developing specific recording forms
			Supervising the patient education
Appropriate educational evaluation	Monitoring patient education record		
	Setting indicators for the effectiveness of education		
	Preparing discharge and postdischarge educational evaluation checklist		

the necessary self-care skills in different areas can increase the effectiveness of patient education in kidney transplantation. "Nutritionist and other health care providers may be very strong educators in their field of work. All of the training should not be undertaken by nurses in my opinion" (Nutritionist D1).

Patient and family accessibility

Patients and their families go to kidney transplant centers around the country. To facilitate access to patients and their family members and to accelerate delivery of training, participants mentioned to provide accommodation facilities for patients and families. "We came from the county and have no place of residence here. We have to go and come and maybe not be available when you have a training program for us" (Family member FM2).

Strengthening human resources

Participants noted that efficient, skilled, and motivated human resources are needed to transition to PFCE.

Empowerment health-care team

Although all health-care teams are expected to provide patient/family education, many lack preparation in the principles of teaching and learning. Participants

pointed to the ability of educators to deliver effective training and considered a lack of knowledge and skills as a serious obstacle to patient education. "The first step is to train staff who are working directly with transplant patients. They (hospital officials) should first train me, for example, how to treat the patients and what education should I give them" (Staff nurse N10).

Allocation of human resources

Because the level of knowledge and skills of the health-care team varies in patient education, and Some of them lack sufficient competence and confidence in teaching skills, participants highlighted on designating a patient education nurse and follow-up nurse in order to integrate and manage patient education program. "No one is responsible for coordinating patient education activities right now. The patient who is discharged must follow up to see if he or she can take care of himself or herself. And provide additional training as needed" (Clinical supervisor S2).

Promoting staffs' motivation

Participants supposed that encouraging staffs to deliver a better patient education could help maintain their performance and improve the performance of others. "What is the difference between Mrs. A, Mr. B, and the

others? One has a good relationship with the patient and is always thinking about training them and the other one is doing some routine works. Is there really no difference between them?" (Clinical supervisor S1).

Updating educational content and materials

One of the problems presented by the participants (both patients and health-care team) was the use of traditional and restricted educational materials and contents in patient education such as booklets and pamphlets. Participants believed that educational content and media should be tailored to learners' needs. "It would be best to provide patients with equipment such as CDs, booklets, pamphlets, and so on if they have a high standard, and to refer them to centers to get answer for their questions after their transplant" (Staff nurse N3).

Monitoring and evaluation

Receiving appropriate feedback from patient and family and evaluating the learning of presented material can determine to what extent the educational goals have been achieved. "In my opinion, we should teach patients and then ask a few questions to see if they have got the information or not. We should do some follow-ups and call patients to see if they have listened to our advice, have gone to see doctor, and what is their creatinine level now, these can be considered as evaluation" (Clinical supervisor S1).

Correcting patient education recording

Patient/family education should be recorded in a way that it would be easily accessible and that all members of health-care team can be informed about the provided education, ensuring that all educational topics are covered. "It is very difficult for me as a nurse to know what my patients have been taught in previous shifts and what is left for me to cover. I have to go through the nursing reports and spend a long time to see what is being taught and what I have to teach" (Staff nurse N1).

Supervising the patient education

Paying attention to patient education occasionally and not supervising staffs' performance in patient education was one of the barriers to effective patient education from the participants' viewpoint. "No attention is paid to our patient education performance. I have personally seen that when a letter or an instruction is issued, staff will comply with it for a few days and then they forget about it and deliver the same education as before" (Staff nurse N6).

Appropriate educational evaluation

The final step in moving toward patient- and family-center education is appropriate evaluation by setting indicators for the effectiveness of education and preparing discharge and postdischarge educational evaluation

checklist. Having clear and transparent educational indicators can help coordinate the health-care team in delivering patient education and evaluation. It can also be used to perform clinical audit of patient education. "We sometimes don't know what we want to achieve in our patient education. We must have a clear purposes and indicators. We also need to know how to evaluate our educational work" (Educational supervisor S2).

Discussion

The findings of the current qualitative study revealed strategies and actions needed to improve education of the individual with kidney transplantation through the transforming to PFCE in a social welfare hospital. PFCE, as an important part of provided health care, is an increasing goal for many health-care organizations and clients as well as it arises as a dimension of quality care.^[22-24] Patient- and family-centered care has been defined as "an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health-care providers, patients, and families."^[25] There was strong evidence for positive outcomes of PFCE.^[26] Windrum *et al.* found that patient-centered education improves blood sugar control and patient participation in self-care than conventional education.^[27] Furthermore, Khanjari *et al.* findings revealed that family-based educational interventions improved the quality of life in adults with spinal injury.^[28] Some studies have been done to find core concepts of patient- and family-centered care^[25] and some seek to translate this concept into measurable behaviors and actions.^[29] However, no study found regarding PFCE in kidney transplantation.

In the present study, comprehensive and continuous patient and family education, facilitating the process, strengthening health-care providers, and monitoring and evaluation have been explained as strategies to implement PFCE. The participants who expressed receiving comprehensive and continuous PFCE in pre- and posttransplant period can increase effectiveness on provided trainings. Many studies have investigated the effect of pretransplant training.^[5,11,30-32] In Browne *et al.* study, insufficient information was identified as a major barrier to kidney transplantation from the patients' perspective.^[30] Starting patient education since renal failure diagnosis, providing educational counseling along with other pretransplant counseling, and preparing pretransplant educational material by kidney transplant centers were suggested as pretransplant educational actions. Many studies have also been done to improve patient education in the posttransplant period.^[4,7,33,34] In our study, individualized patient and family education, concurrent patient and family education, and developing inpatient and postdischarge/follow-up patient and

family education guideline describe as actions for PFCE in the posttransplant phase. Individualized and tailored patient education may be an effective strategy to improve knowledge and disease control indicators.^[35] In a study of renal transplant recipients' experiences of participating in a new, tailored, evidence-based education program, it was found that they feel more satisfied with receiving individualized education.^[36] On the other hand, participants stated that facilitating the processes using new technologies, teamwork education, and patient and family accessibility is necessary to achieve PFCE. Studies have shown that using remote technology-based education such as websites, smartphone applications, and social networks as a strategy has increased knowledge, medication adherence, and patient education effectiveness in transplanted recipients.^[37-39] From the participants' point of view, teamwork patient education was one of the key elements of patient education. This is consistent with the study of Farahani *et al.*, in which lack of collaboration and coordination between health-care providers in health education was identified as a problem by the participants.^[40] In our study, participants also stated that facilitating patient and family access to a kidney transplant center during kidney transplant process could increase the quality and quantity of received education. This finding is consistent with the study of Preussler *et al.*, in which caregiver availability is an important concern for patients considering and receiving hematopoietic cell transplantation, and maybe a barrier proceeding to hematopoietic cell transplantation when a caregiver is unavailable.^[41]

Health-care providers are expected to educate patients in a variety of fields as part of their professional duties, but few of them have had a specific training on teaching and learning principles, and many of them feel uncomfortable and lack self-confidence in their patient education skills.^[42] Participants in the present study believed that educational empowerment of the health-care team could play an important role in promoting patient education, which is consistent with other studies in which nurses believed that their inadequate knowledge and skills were the main obstacles to patient education.^[40,43] Holding patient education workshops and developing patient education content for the health-care team were among the strategies proposed by the participants. In our study, the participants suggested that designating patient education and follow-up nurse is necessary to provide integrated and continuous education in the postkidney transplant period. This finding is consistent with the study by Khorasani *et al.*, which emphasized expanding nurses' role in patient education and allocating patient education nurse, as an organizational model for solving patient education problems in Iran.^[44]

Promoting staffs' motivation reinforced by other incentives and efforts to establish a culture of patient education mentioned by the participants. In the qualitative study of Farahani *et al.*, increasing motivation through strengthening the organizational culture in the health-care organizations was mentioned by the participants as an effective strategy for improving PFCE.^[40]

Wilson *et al.* emphasized the use of appropriate educational material and content.^[34] Participants in our study state that updating educational content and material can help health-care professionals deliver effective patient education.

Finally, continuous monitoring and evaluation through correcting patient education recording, supervising the patient education, and appropriate educational evaluation were identified as measures that can be taken to promote PFCE. The patient education records used by health-care organizations can also affect the quality and quantity of patient education. Most of the training provided is not recorded due to the lack of time, lack of attention to detail, and lack of specific forms. It is necessary for health-care workers to choose an appropriate method of recording.^[42] In the present study, the participants suggested that specific forms for recording of patient education in kidney transplantation should be prepared as a solution to this issue. Because of the cyclical nature of patient education process, evaluation at the end of each cycle provides reliable evidence to guide the next cycle.^[42] The study of Seyedin *et al.* showed that evaluation is not properly addressed and nurses do not use any strategies to evaluate the effectiveness and efficiency of educational programs.^[45] In our study, formulation of effectiveness indicators and preparation of educational evaluation form during hospitalization and after the discharge were suggested as strategies of educational evaluation.

Conclusions

Shifting from the current patient education program to PFCE seems to be essential to increase the effectiveness of patient education in kidney transplant process. To this end, providing comprehensive and continuous patient and family education, facilitating the processes, strengthening human resources, and monitoring and evaluation in health-care organization conducting the kidney transplantation is necessary.

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Conflicts of interest

There are no conflicts of interest.

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