

Self-Care Education Program as a New Pathway Toward Improving Quality of Life in Kidney Transplant Patients: A Single-Blind, Randomized, Controlled Trial

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Abstract

Objectives: Despite the benefits of kidney transplant, kidney recipients are confronting many challenges that affect the quality of their lives. Implementation of the most effective self-care education program based on the needs of patients may address these challenges and improve their quality of life. This study aimed to determine the effects of a self-care education program on the quality of life in kidney transplant patients. **Materials and Methods:** In this single-blind, randomized, controlled trial, 59 patients who met inclusion criteria were selected using a convenience sampling technique. Patients were randomly allocated into intervention (n = 29) and control (n = 30) groups. The intervention group received a bedside self-care education program in 3 sessions. The control group only received routine care. Data were collected by demographic and kidney transplant questionnaires before and after the intervention. Measuring the mean score of quality of life was the primary outcome in this study. We used descriptive and inferential statistics to analyze the data.

Results: A significant difference was observed in the mean score of quality of life between both groups

after intervention ($P < .001$). The mean score of quality of life increased significantly in the intervention group after the self-care education program ($P < .001$).

Conclusions: A self-care education program is a more effective approach to improve the knowledge and skills of transplant patients. Thus, we suggest an emphasis on teaching self-care knowledge and skills for transplant patients in nursing care education programs. This can ultimately lead to quality of life improvement in kidney transplant patients.

Key words: Clinical trials, Iran, Nursing, Patient education

Introduction

One of the world's major public health problems is end-stage kidney disease (ESKD).¹ About 678 383 people in the United States in 2014 were diagnosed with this disease, and the cost of treatment reached 32.8 million dollars at the end of 2014.² In Iran, the overall prevalence of ESKD was reported to be 17.14%, which is higher than the world average.³ The major problems of patients with ESKD include sexual issues, cardiovascular disease, anemia, hyperlipidemia, metabolic bone disease, and lack of awareness of their disease. Patients should be treated by therapeutic modalities such as hemodialysis and kidney transplant to reduce complications and decrease morbidity and mortality.⁴ Hemodialysis is a high-cost treatment and has many problems such as long-term dependency on the hemodialysis machine and anxiety in the patient. Hence, patients prefer kidney transplant in order to maintain their lives and avoid the consequences of the illness.⁵ Despite the benefits of kidney transplant, kidney transplant recipients confront many challenges such as a strict medication regimen and its side effects, repeated medical visits, the probability of infection, fear of organ rejection, and fear of death, all of which affect the quality of their lives.⁶

The World Health Organization in 2000 has defined the concept of quality of life (QOL) as the

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personal perception of one's situation and culture, the value system in which one lives, and one's goals, expectations, standards, and priorities. This concept has different dimensions that affect one's physical health, mental status, independence, social relationships, and personal beliefs.⁷ Quality of life is a valuable indicator for measuring health status in public health and medical research. Access to QOL information, in addition to providing appropriate treatments, may also be effective in promoting treatment programs, self-care education, and rehabilitation.⁸

Presently, expectations of patients after kidney transplant have changed from merely reducing pain and increasing activity to a higher expectation of achieving a long-term active lifestyle.⁹ The measurement of QOL helps nurses to support those patients whose QOL factors are at risk, possibly compounded by impaired organ function.¹⁰ A recent study has shown that activities related to improving the QOL of kidney transplant patients not only reduced the length of hospital stay and medical costs but also promoted an active lifestyle and provided encouragement to resume some activities, thereby increasing the self-care ability of patients.¹¹

Self-care is a practice in which each person uses personal knowledge, skill, and ability as a resource by which to maintain care of oneself independently.¹² Self-care is the most important type of primary care in developed and developing countries.¹³ It is estimated that 65% to 85% of care is provided by the patient and his or her family without the involvement of health care providers.¹⁴ This shows that the patient education program is an integral part of primary and specialized care plans that facilitates the implementation of self-care and improves the health, economic status, and social status of the patient and his or her family.¹⁵ Patient education is a process by which health care professionals provide general and specialized information to patients. This information is taught on the basis of the needs of patients, out-of-hospital care, proper methods of self-administering medications, and potential improvements in QOL.¹⁶ The primary objective of a patient education program is to change patient behaviors according to their health conditions. These behavioral changes may lead to increased levels of patient health, delayed progression of disease, and ultimately, increased self-care capacity in patients.¹⁷ Self-care education is one of the key concepts in

patient education. Self-care education seeks to create a sense of responsibility for health promotion in any person. In successful self-care, the patient achieves a level of self-confidence that can facilitate responsible decisions regarding his or her health.¹⁸ It has been proved that patient education and self-care enhancement may reduce hospital expenses by 20%.¹⁹ The most important goal in self-care education is reducing the complications of surgery and, consequently, reducing mortality rates in kidney transplant patients.²⁰ Empowering patients through self-care education may help improve self-management, reduce pain and possible surgical complications, and enhance knowledge and improve skills to make decisions and solve problems.²¹ Once self-care ability is mastered by these patients, their ability to make decisions and to adapt will be enhanced. Thus, the purpose of educating these patients is to help them to take more responsibility for their self-care and help them to adapt to changes in their physical and functional state.

Hence, implementing the most effective self-care program based on the needs of patients after kidney transplant may help to solve their problems and improve the quality of their lives. Thus, this study was carried out to determine the effectiveness of self-care education program on QOL in kidney transplant patients. Our hypothesis was that the self-care education program might have an impact on the QOL of kidney transplant patients.

Materials and Methods

Design and participants

This single-blind, randomized, controlled trial was performed from May to July 2018. The study population consisted of kidney transplant patients who were referred to Imam Reza Hospital in Tabriz. The inclusion criteria for patients were as follows: age between 18 and 60 years old, willingness to participate in the study, ability to read and write, absence of serious underlying diseases such as cancers and Alzheimer disease (which could impair QOL), and access to a phone. Exclusion criteria were as follows: absence from more than 1 education session, unwillingness to stay in the study, immigration, and death of patients. The researcher consulted the statistician to calculate the sample size. Based on previous study, by considering $\alpha = 0.05$, power of 0.80%, and effect size of 0.8, the sample size was

calculated to be 52 patients by using G-Power version 3.1.2 (Heinrich Heine University, Dusseldorf, Germany). To anticipate a 10% attrition rate, 60 patients entered the study.²² Patients were selected using convenience sampling, so that 60 patients who were eligible for participating in the research were selected. Then, the samples were randomly allocated to the intervention (n = 30) and control (n = 30) groups (Figure 1).

Intervention

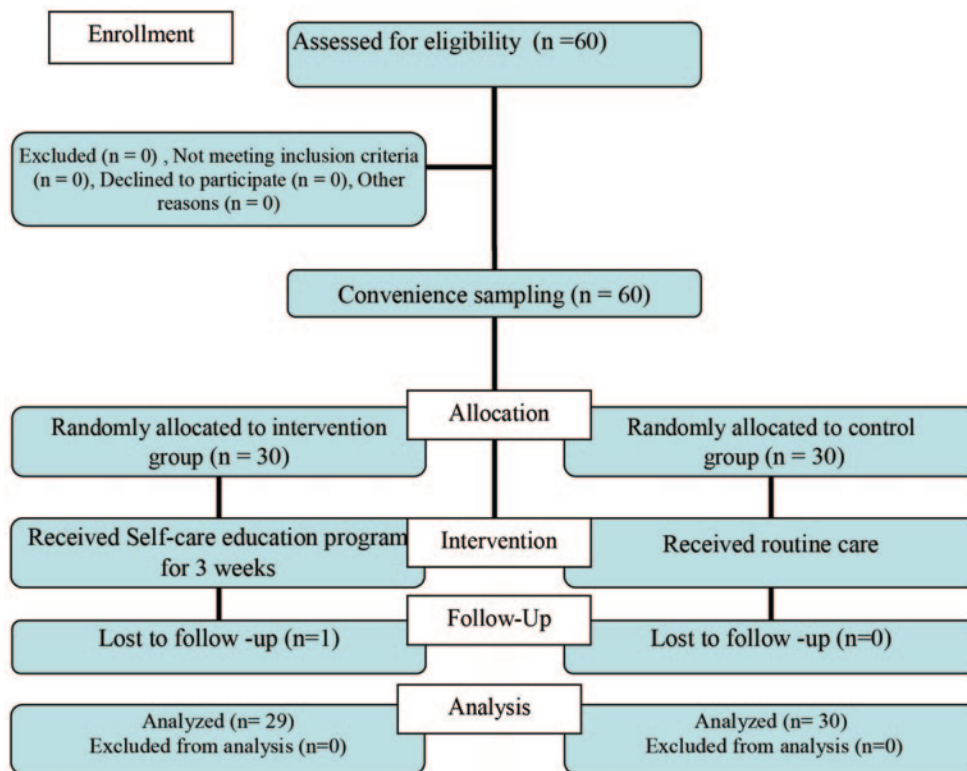
After obtaining permission from the university research and ethics committee, the researchers visited the nursing manager at the hospital to explain the purpose of the study and also coordinated with other hospital authorities. In this study, sample randomization was based on hospital identification numbers (assigned to all patients at intake, as a matter of general hospital policy), so that the patients whose numbers were odd were put into the intervention group, and patients whose numbers were even being put into the control group.

In the first step, the researcher introduced himself to the patients, gave them the necessary information

regarding the study, and ensured them about the confidentiality of information. After eligible participants signed the consent form, the researcher completed the questionnaire by face-to-face interview. The researcher identified the patient education needs during the interview. A trained researcher then extracted self-care education programs from scientific resources. The researcher prepared the education package after consulting with a nephrologist. In the second step, we identified patient care needs and their self-care ability. We performed individual and face-to-face education programs by using an educational booklet at the bedside in 3 sessions of 30 to 45 minutes every other day. We implemented this program during morning, evening, or night shifts based on the comfort and convenience of each patient. The control group had no intervention, and they received only routine care. In the third step, we had a meeting with all patients at the nephrology clinic 2 months after the last training session. The questionnaire was completed again for the patients in both groups.

In the first education session, the content of the educational program was about the nature of the

Figure 1. Flow Diagram of the Study Based on Consolidated Standards of Reporting Trials Statement 2012



For information on the Consolidated Standards of Reporting Trials, see <http://www.consort-statement.org/>.

disease, its etiology, clinical symptoms, diagnosis, treatment, and complications. In the second session, we explained the principles of medication administration and side effects. We taught the patients regarding diet regimen and physical and self-care activities in the third session (Table 1).

Table 1. Steps and Content of the Self-Care Educational Class

| Classroom Self-Care Training Steps | Content of the Package at Each Educational Step |
|------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| First step | Definition of chronic renal failure; causes of disease; signs and symptoms, complications of disease; diagnosis and treatment What is chronic kidney disease? What causes this disease? What are the signs and symptoms of this disease? What are the possible complications? What are the diagnostic tests and procedures? What are the treatment options for this disease? |
| Second step | Medications What are the medications for chronic kidney disease? What are the important side effects? How does one properly administer the medication? |
| Third step | Diet regimen What is the appropriate diet for patients with chronic kidney disease? What foods should be avoided? What foods should be included? Physical activities What are the best physical activities for these patients? Self-care activities What measures should one take to prevent infection? How long after a kidney transplant can one begin sexual activity? Is pregnancy permitted after transplant? |

Instruments

Two questionnaires were used in this study. The demographic information questionnaire included age, sex, marital status, residence status, education, employment, income, family history of kidney failure, specific illness, history of transplant rejection, duration of disease, duration of hemodialysis, and and wait time for transplant. The Kidney Transplant Questionnaire (KTQ-25), developed by Laupacis and colleagues in 1992, is used to measure QOL in kidney transplant patients.²³ Twenty-five items in the questionnaire are classified in 5 dimensions: physical symptoms, fatigue, uncertainty/fear, appearance, and emotions. The questionnaire measures the QOL of transplant patients, according to their problems. Scoring of the questionnaire is based on responses obtained on a 7-point Likert scale (with highest score of 7 and lowest score of 1). First, the total score of each dimension are added together, then divided by the numbers of questions of each dimension. In the end, the final score of each dimension is obtained. The lowest score represents the lowest QOL and vice versa.

The validity of this questionnaire was confirmed by 15 specialists and professors of the Tehran University of Medical Sciences. The reliability of the scale was measured by the Cronbach alpha coefficient and intraclass correlation coefficient. The Cronbach alpha coefficient was satisfactory for the entire scale ($\alpha = 0.93$) and all dimensions of physical symptoms ($\alpha = 0.86$), fatigue ($\alpha = 0.85$), uncertainty/fear ($\alpha = 0.79$), appearance ($\alpha = 0.73$), and emotion ($\alpha = 0.84$).²⁴

Statistical analyses

One of the patients in the intervention group was excluded because the patient relocated to another city. Finally, 59 patients were analyzed. The researcher who was blinded to the data analyzed the data by using SPSS software (version 22; IBM). We used the Shapiro-Wilks test to check the normality of the data. To analyze the data, we used descriptive statistics (mean, standard deviation, number, and percentage) and inferential statistics (chi-square, Fisher exact test, Mann-Whitney U test, independent *t* test, ANCOVA).

This study is registered as Irct20160220026662N3 with ethical approval code Ir.umsu.res.1396.350.

Results

There were no statistically significant differences between the 2 groups with regard to the variables of sex, marital status, family history of kidney failure, specific disease, education level, place of residence, income, occupation, and history of transplant rejection (Table 2).

There were no statistically significant differences between 2 groups with regard to age, duration of disease, and duration of hemodialysis. An independent *t* test revealed statistically significant differences with regard to posttransplant time and transplant wait time between the 2 groups (Table 3).

Independent *t* tests showed significantly different QOL scores between the 2 groups after the self-care education. We used the ANCOVA test to control the effect of confounding variables in patients; it showed a statistically significant difference between the 2 groups in QOL after self-care education ($P < .001$) (Table 4).

Total mean score was significant in both groups before and after the intervention. However, the mean

score decreased in the control group and increased in the intervention group. Thus, the intervention significantly increased the mean QOL total score (Table 4).

Table 2. Comparison of Demographic Characteristics of Patients Between Intervention and Control Groups

| Variable | Control Group, No. (%) | Intervention, Group No. (%) | P |
|----------------------------------|------------------------|-----------------------------|----------------------|
| Sex | | | |
| Female | 13 (43.3%) | 18 (62.1%) | .15 |
| Male | 17 (56.7%) | 11 (37.9%) | ($\chi^2 = 2.076$) |
| Marital status | | | |
| Single | 4 (13.3%) | 5 (17.2%) | .223 |
| Married | 26 (86.7%) | 21 (72.5%) | (F = 3.272) |
| Divorced | 0 (0%) | 3 (10.3%) | |
| Family history of kidney disease | | | |
| Yes | 1 (3.3%) | 1 (3.4%) | .981 |
| No | 29 (96.7%) | 28 (96.6%) | ($\chi^2 = 0.001$) |
| Specific disease | | | |
| Yes | 11 (37.9%) | 8 (27.6%) | .401 |
| No | 18 (62.1%) | 21 (72.4%) | ($\chi^2 = 0.704$) |
| Education level | | | |
| Elementary | 14 (46.7%) | 20 (71.4%) | .123 |
| High school | 14 (46.7%) | 6 (21.4%) | ($\chi^2 = 4.194$) |
| University | 2 (6.7%) | 2 (7.1%) | |
| Place of residence | | | |
| Owner | 19 (67.9%) | 20 (83.3%) | .199 |
| Rental | 9 (32.1%) | 4 (16.7%) | ($\chi^2 = 1.651$) |
| Occupation | | | |
| Unemployed | 13 (46.4%) | 15 (51.7%) | .782 |
| Employed | 8 (28.6%) | 6 (20.7%) | ($\chi^2 = 1.078$) |
| Disabled | 5 (17.9) | 7 (24.1%) | |
| Retired | 2 (7.1%) | 1 (3.4%) | |
| Income | | | |
| More than expense | 2 (16.7%) | 1 (9.1%) | .782 |
| Less than expense | 4 (33.3%) | 5 (45.5%) | ($\chi^2 = 0.493$) |
| Equal to expense | 6 (50%) | 5 (45.5%) | |
| History of transplant rejection | | | |
| Yes | 1 (3.6%) | 1 (3.4%) | .98 |
| No | 27 (96.4%) | 28 (96.6%) | ($\chi^2 = 0.001$) |

Table 3. Comparison of Demographic Characteristics of Patients Between Intervention and Control Groups

| Variable | Control Group | Intervention Group | P |
|----------------------------|---------------|--------------------|--------|
| Age, y | 41.5 ± 12.12 | 42.72 ± 15.01 | .731** |
| Duration of the disease, y | 5.05 ± 4.3 | 4.34 ± 3.38 | .308* |
| Duration of dialysis, y | 2.53 ± 2.09 | 1.87 ± 1.96 | .068* |
| Posttransplant time, mo | 11.13 ± 1.25 | 6.3 ± 1.98 | .001* |
| Transplant wait time, y | 2.23 ± 0.23 | 1.75 ± 0.38 | .014* |

Values are means ± standard deviation. *Mann-Whitney U test. **Independent t test.

Table 4. Comparison of Mean Scores of Quality of Life in Kidney Transplant Patients in the Groups Before and After Self-Care Education

| | Before Self-Care Education | After Self-Care Education | Paired t Test |
|--------------------|----------------------------|---------------------------|---------------|
| Control group | 5.244 ± 0.527 | 5.175 ± 0.567 | P = .005 |
| Intervention group | 4.836 ± 0.641 | 6.017 ± 0.546 | P < .001 |
| | P = .01 | P < .001 ^a | |

Values are means ± standard deviation. ^aANCOVA.

Discussion

The results showed a significant difference in mean score of QOL between kidney transplant patients who received a self-care education program and those who did not. This confirms the positive effect of education on the QOL of kidney transplant patients.

Similar to our findings, Gentile and colleagues reported that lack of education is associated with poor QOL in kidney transplant recipients and that implementing therapeutic education programs can improve QOL in these patients.⁶ In a study conducted by Amiri and colleagues, patients who participated in a self-care education program and consulted with nurses and other health care providers about performing self-care behaviors had better performance and safety outcomes.²⁵ In line with our study results, Chen and Li confirmed the positive effects of empowerment interventions on improving QOL in patients with chronic diseases.²⁶ A recent study showed that social empowerment interventions are effective in improving QOL in patients with chronic diseases.²⁷ Improving the QOL in patients with kidney transplant was considered as a part of the care plan that can be used to decrease the incidence of transplant rejection and to minimize adverse effects of immunosuppressive drugs.²⁸

We believe that the high QOL scores of our transplant patients were the result of a proper self-care education implemented by our research team. Education for kidney transplant patients is an integral part of postoperative care, and improving the QOL for patients largely depends on their awareness, motivation, and family support. Brett and colleagues also stated that accessibility of health services, access to treatment, clear and effective communication with the patient, comprehensive multidisciplinary care, patient satisfaction with care, supportive attitude among health care personnel, patient-centered care, and patient safety are the important factors affecting the QOL.²⁹ Our findings were also confirmed by the following studies. A recent survey reported that implementing self-management program significantly improved the QOL among kidney transplant patients.³⁰ Another study revealed that the patient education program had a positive effect on coping, QOL, knowledge, and self-efficacy of kidney transplant patients.¹⁵

Weng and colleagues confirmed the relationship between patient self-efficacy and self-care behavior. They claimed that self-efficacy had a direct effect on self-care behavior and indirectly influenced the QOL.³¹ Self-care education programs have improved patients coping strategies in dealing with kidney posttransplant consequences, reducing stress, and promoting self-efficacy and QOL.¹⁵ Numerous studies have confirmed the positive effects of a self-care education program on the QOL of kidney transplant patients.^{15,32}

Several recent studies have confirmed the effects of many demographic factors (such as sex, age, level of education, marital status, income) on QOL of patients.³³⁻³⁶ Accordingly, these factors play essential roles in assessing personal QOL.³³ Thus, it is necessary to assess and ensure that there is no difference regarding demographic characteristics between the 2 groups. In our study, there was no statistically significant difference between our 2 study groups in terms of age, sex, marital status, education, occupation, income, and duration of illness. This means that our 2 groups were homogeneous and that the improvement of QOL scores in the kidney transplant patients in our study was the result of the self-care education program.

This study has some limitations. First, there was a significant difference between the 2 groups with regard to posttransplant time and transplant wait time, which could affect QOL of patients. Therefore, we suggest similar studies should be conducted after matching the transplant wait time and posttransplant time between the 2 groups to get more accurate results. Second, our study was carried out in a small region with its own specific culture; it is known that the culture of a region has an impact on learning and ability to implement lessons learned. Thus, other studies are recommended in other, larger regions with different cultures. Third, the mental and emotional state of the participants is another limitation that could have an impact on the findings. Thus, the study results should be generalized with caution.

Conclusions

The results indicated a positive and direct link between the self-care education program and QOL in kidney transplant patients. It seems that an appropriate self-care education program may help control the consequences of kidney transplant. Self-

care education is the most effective way to improve the knowledge of kidney transplant patients and their QOL. Nurses have an important role in interacting with these patients, and nurses can provide the necessary knowledge, skills, and support to their patients. Hence, we suggest that, in nursing care education programs, an emphasis should be placed on teaching self-care knowledge and skills to transplant patients.

The findings of this study can be applied in different areas of nursing, such as nursing education, nursing management, nursing practice, and nursing research. By empowering nursing students regarding self-care education, these nurses may effectively educate their patients and help them to improve their self-care skills, ultimately leading to QOL improvement in transplant patients.

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