Effect of Self-Management Program on Quality of Life for Patients with Chronic Kidney Disease

Rania Rabie El-Etreby[*], Ahmed Hashem El-Sayed El-Monshed

Lecturer of Psychiatric and Mental Health Nursing, Faculty of Nursing-Mansoura University
*Corresponding author: rania.etreby@yahoo.com

Abstract   **Background:** Chronic Kidney Disease (CKD) is a serious medical and public health problem whose prevalence is increasing worldwide. Patients with CKD must cope with life changes and stresses to improve their quality of life (QoL). It is suggested that self-management is key to the effective care of chronic diseases, a process in which individuals carry out the daily functions of health care to manage chronic diseases. **Aim of the study:** This study aimed to evaluate the effect of self-management program on QoL among patients with CKD. **Subjects and Method:** A quasi-experimental research design [pretest -posttest] was conducted at Out-Patient Clinics of the New Mansoura General Hospital. The instruments used for data collection were Socio-demographic and Clinical Data Structured Interview Schedule and The 36-item Short-Form Questionnaire (SF-36). A convenience sampling of sixty nine patients with CKD completed the study after implementing the self-management program with 6 weekly sessions. **Results:** The present study findings revealed that there was highly statistically significant difference of all dimensions of QoL except pain and vitality/ energy dimensions between before and after implementing the self-management program. **Conclusion**: The current study revealed that the CKD self-management program had a positive effect on preventing QoL deterioration in patients with CKD. **Recommendation:** Self- management programs will be useful if it is accompanied by other therapeutic and welfare actions and comprehensive supports of public and private charity organizations.

Keywords: *chronic kidney disease, quality of life, self-management*

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1. Introduction

Chronic Kidney Disease (CKD) is one of the most serious public health problems that is increasingly prevalent world-wide [1]. It is predictable that in the world, diseases of the kidney and urinary tract account for about 850 million deaths every year, and the incidence of CKD is increasing by around 8% every year [2].

As of today, there is no cure for CKD. Patients require kidney replacement therapy; kidney-transplantation (2.6% of CKD patients) and either dialysis; hemodialysis or peritoneal; 97.2% [3,4].

Although treatment is a difficult and painful experience, the patient must be presented as soon as possible to it for maintenance of the life [2]. In addition, CKD leads to poor health results, lower quality of life (QoL) and more health care costs. CKD Patients frequently suffer from much co-morbidity, such as cardiovascular disease, diabetes and depression. They need for balances between the medical treatment of CKD and chronic conditions with the requirements of their everyday life-times, including management of psychological and social outcomes to live with chronic disease [5].

Patients with CKD usually need for hemodialysis treatment, which is expensive, time-consuming, and requires dietary and fluid restrictions. Long term treatment of hemodialysis frequently leads to loss of autonomy; reliance on caregivers; disturbance of interpersonal and social-relationship; and poor financial income. Hemodialysis treatment changes the lifestyle of both patient and his/her family. The main aspects of life influenced by CKD and hemodialysis include sense of security, work, nutrition, vocational activities, self-esteem, social-relationships, and life-satisfaction. Owing to these causes, the bio-psycho-socio-economic and environmental areas of life are negatively influenced, resulting in deteriorating QoL [6].

Psychological symptoms such as anxiety and depression are common in CKD patients. Mood disorders are usually diagnosed both clinically and administered suboptimal in CKD patients. Assessment of symptoms of depression and anxiety in patients with CKD is significant because these disorders of mood are closely related to poor quality related health [7].

Hemodialysis patients need to improve personal resources to meet challenges and burdens triggered by the invasive and permanent effects of CKD on physical and psychological health, in addition to their QoL domains

such as family domain, lifestyle domain, relationship and communication domain, and occupational domain [4].

The World Health Organization Quality of Life Group defines the term QoL as: "The individual's perception of his situation in life in the context of the culture and value system in which he lives and in relation to his goals, expectations, standards and concerns." As an individual's interpretation of one's habit is individual, QoL is multi-dimensional and subjective, considering emotional, physical, social, psychological, cultural, and family criteria among others [8].

Care for all aspects of CKD that can improve QoL in patients with CKD is essential, and therefore strengthening the coping strategies and improving QoL in CKD patients has become a relevant area of investigation. Furthermore, patients with CKD have the responsibility for self-care to reduce the bio-psycho-social, and spiritual effect of their illness and its treatment [1].

Self-management is a broad concept that refers to the duty of patients and their ability to live a healthy life-style. Also, self-management can be defined as the essential aspect for individuals to treat acute illnesses and expand the chronic ill patients with appropriate health-care [9].

The term self-management consists of the words "management" and "self". Management has to do with motivation, planning, goal setting, resource calculation, control, and a monitoring based on the assigned task. The self, on the other hand, has a double meaning: it refers to an autonomous, self-contained subject, without any external intervention, and at the same time the subject is the object of the action [10].

Self-management is significant in the management of chronic illnesses, a process in which individual carries out the everyday functions of healthcare to manage chronic diseases. Self-management improves patient's self-confidence, knowledge, and skills of circumstances, helping these patients to manage their illnesses **[11]**.

In other words, adequate levels of self-management improve, in fact, the QoL, reduce mortality and use of health services. Self-management skills, particularly help patients make conscious choices leading towards a therapeutic adherence and a satisfying life [10].

A systematic review of prior studies suggested that the self-management interventions for patients with chronic illnesses, especially with CKD, including self-efficacy training program, self-monitoring, emotional management, relaxation techniques, cognitive behavioral interventions, and educational intervention [9].

Today, nurses can make significant assistance due to their experience, focus on daily life, and the bridge function between patients and health professionals in different healthcare settings. The important role of nurses in self-management interventions has been demonstrated with positive results. Self-management interventions help nurses to bring ideas into action. The open and repetitive process encourages thinking outside the box and considering less obvious solutions [12].

2. Significance of the Problem

In Egypt, the CKD incidence per year is about 74 per-million and the prevalence of dialysis patients on dialysis is 264 per-million [13]. A considerable number of studies proved that problems associated with CKD and its treatment led to a decrease in QoL of patients [14]. Poor QoL may weaken the self-management of their disease and lead to worsening conditions [11]. Therefore, it is deemed necessary to conduct this study to evaluate the effect of self-management program on QoL among patients with CKD.

3. Aim of the Study

This study aimed to evaluate the effect of self-management program on QoL among patients with CKD.

3.1. Hypothesis

The self - management program improves the QoL among patients with chronic kidney disease.

3.2. Methods

3.2.1. Research Design

A quasi experimental research design [pretest -posttest] was used in the current study.

3.2.2. Setting

The study was conducted at the Out-Patient Clinics of the New Mansoura General Hospital affiliated to the Ministery of Health and Population.

3.2.3. Subjects

A convenience sampling of sixty nine visited the out-patient clinics every three months for follow-up was recruited using the following inclusion criteria: (1) patients diagnosed with CKD for 6 months or more; (2) age is eighteen years or more; (3) On hemodialysis treatment during the study time; (4) consent to participate in the study; and (5) Patients who have the ability to read and write. Patients with malignancy or any other physical or mental disabilities that affect their abilities to participate in the study were excluded**.**

3.2.4. Tools of Data Collection

The following two tools were used for data collection

- Tool one: Socio-demographic and clinical data Structured Interview Schedule included two parts:-

Part I: Patient's socio- demographic data as (age, sex, residence, marital status, educational level, and occupation).

Part II: Patient's clinical data as (medical co-morbidity, duration of illness, and mode of treatment).

- Tool two: The 36-item Short-Form Questionnaire (SF-36):-

The 36-item Short-Form Questionnaire (SF-36) was developed by (MCS; [15]). It is a self-administered questionnaire that is not limited to any illness or treatment group. This tool was translated into Arabic and tested for its content validity and reliability by Hassan [16] using test retest reliability Spearman's correlation coefficient (r= 0.88). The SF-36 consists of 36-item resulting an 8- dimension profile. These dimensions include: General

health, Pain, Physical functions, Vitality-energy, Role limitations due to physical problems, mental health-emotional well-being, Social functions, and Role limitations due to emotional problems-mental health. All items refer to a perceived health situation over the last 4 weeks.. Likert scale and yes or no answers are used to evaluate functions and well-being. For SF-36 scoring, scales are standardized with a scoring algorithm to gain a score ranging from 0 to 100. A higher score indicates better QoL.

3.2.5. Intervention

The CKD self-management program was designed by the research team based on the self-efficacy theory that focuses on the individual's belief in their ability to manage their performance and situations that influence their life. Belief in self-efficacy influences life-choices, motivation, performance quality, and resilience to depression, anxiety, and stress [17,18].

Each patient was planned to present a 6-week self-management program that included face to face group sessions of ten to twelve patients for 45-60-min per week. At first, the researchers led discussions in which patients educated about the self-management program and its process, including: suggest health problems of the patient to be recognized in the management of illness; monitor and address factors triggering physical and psychological problems; learn effective coping strategies; setting up applicable individualized goals; developing particular methods to achieve goals; self-evaluation of the effectiveness of these methods; and recognizing individual own outcomes.

After each session, patients were guided for monitoring and recording their daily activities through a workbook of self monitoring, in which patients can monitor and recognize potential causes or situations that cause management problems. Group discussions, homework, psycho-education, and various media such as graphics and images are various methods and techniques used in applying the program. The details of the self-management program are shown in Table 1.

Table 1. Chronic Kidney disease self-management program

| Session	Goals	Program activities
First Week	1. Establish interactive communication between the researchers and the group members. 2. Understand the importance of self-management program. 3. Understand self-management process in disease management.	1. Develop a written and verbal protocol for cooperation between the researchers and members of each group. 2. Ice breaking can be an effective method of beginning a training session or team building event. 3. Explain the importance of self-management program. 4. Identify self-management process in disease management.
Second Week	1. Identifying physical and psychological problems to be addressed. 2. Has the ability to use the workbook of self monitoring.	1. Discuss potential problems and stressors that may be triggered with CKD. 2. Guide patients in prioritizing and addressing problems. 3. Reveal how patients have to monitor and record everyday activities through the workbook of self monitoring at home.
Third Week	1. Learn effective coping strategies.	1. Patients share self monitoring activities in the last seven days. 2. Through group discussion, researchers will provide psycho-education about effective coping strategies to face CKD problems and stressors. 3. Demonstrate how patients should monitor and record their coping strategies using Coping with Stressors Worksheet at home.
Fourth Week	1. Setting up applicable individualized goals 2. Developing particular methods to achieve goals 3. Training on problem solving strategies for patients' utilization in identifying the best technique for dealing with difficulties or situations related to CKD.	1. Patients share self monitoring activities in the last seven days. 2. Discuss differences between patients' coping strategies and identify the ideal strategies for disease management groups. 3. Identifying personal goals and discussing effective methods to achieve these goals. 4. Train patients on generating alternatives record technique and steps of problem-solving. 5. Recommend that each patient applies problem-solving skills by following the steps of problem solving.
Fifth Week	1. Self evaluation of the effectiveness of methods used for achieving the personal goals. 2. Mastering relaxation techniques for emotional management.	1. Guide patients for reviewing their goal achievement. 2. Discussing difficulties and barriers in developing plans. 3. Analyzing causes for goals achievement failure. 4. Developing new methods for goals achievements by group brainstorming and problem solving skills. 5. Train patients on relaxation techniques: deep breathing exercise and mindfulness meditation. 6. Practice the learned techniques between sessions at home with written feedback.
Sixth Week	1. Evaluate efficiency of the new methods. 2. Recognizing individual's own outcomes.	1. Evaluate the efficiency of new methods. 2. Summarize significant aspects of CKD self-management. 3. Reevaluating and prioritizing stressors and coping strategies.
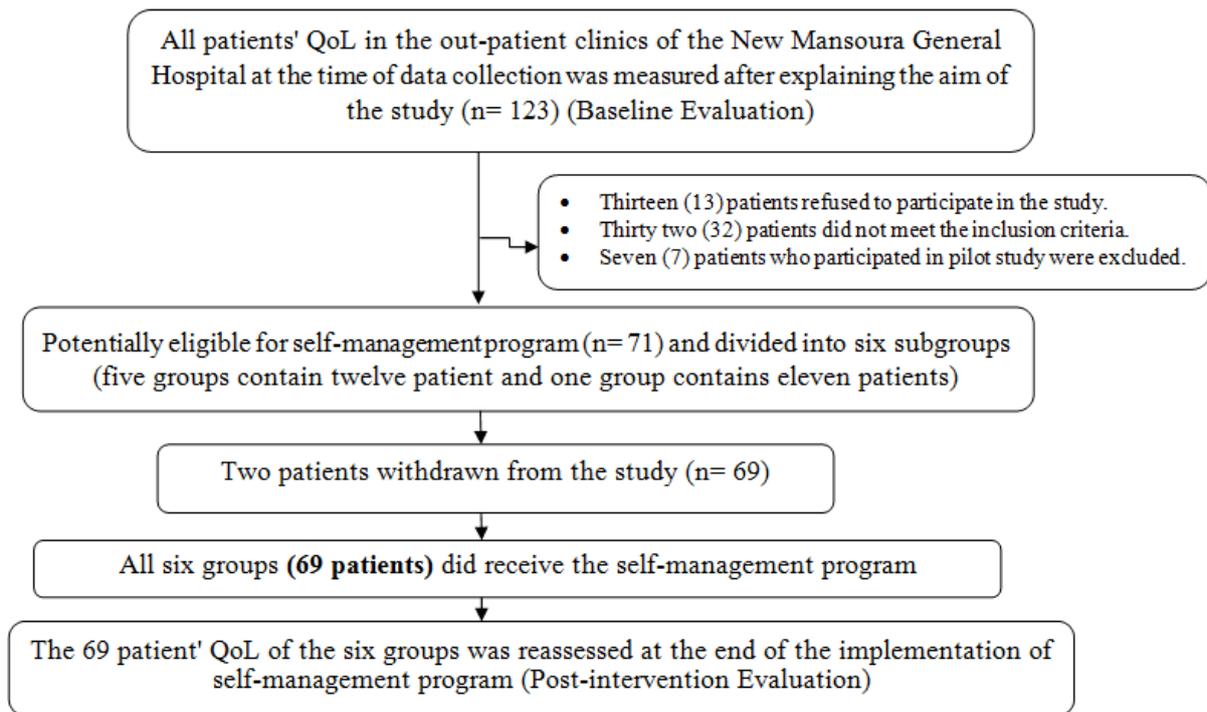
Figure 1. Schematic of Patients Recruitment and Study Procedures as Modeled by the Researcher

3.2.6. Field Work and Procedures

Permission was granted from the manager of the health care providers and the head nurse of the Out-Patient Clinics of the New Mansoura General Hospital were informed about the aim of the study, time of data collection and all necessary details to gain their cooperation during the data collection process.

Tool (1) was developed by the researchers after reviewing the related literature. It included socio- demographic and clinical data related to the subjects. A pilot-study was conducted on seven patients with CKD attending the Out-Patient Clinics of the New Mansoura General Hospital to test the clarity and applicability of the instruments used, also to define the time required for completing the instruments. Patients who participated in the pilot-study were excluded from the study sample.

Individually, each patient was interviewed to obtain the required data. The researchers introduced their self to the patient at the beginning of the interview, and discussed the aim of the study. Applying tool 2 to assess QoL of CKD patients. Evaluation phase was started immediately after the last session of the program to assess the effect of the program using the study tool 2.

The study was carried out through two months from November 2018 to December 2018. The researchers attended the waiting area of the Out-Patient Clinics of the New Mansoura General Hospital from 9.00 am to 11:00 am for three days per week. Baseline data was collected in the first week of data collection. During the next week, self-management program was applied in group form, two groups per day. Patients' recruitment and study procedures in details are shown in Figure 1.

3.2.7. Ethical Consideration

1. The requisite formal approvals were attained from the director of the New Mansoura General Hospital.

2. Patient' informed consent was obtained from each patient after explaining the purpose and the significance of the study.

3. Patients were having right to participate or not participate in the study.

4. Maintain privacy and confidentiality for each patient involved in the study.

5. Demonstrating that all data will be used only for scientific research.

3.3. Statistical Design

In the current study, researchers used SPSS 24. The data normality was firstly examined by one sample Kolmogorov Smirnov test. Qualitative data were presented using numbers and percentage. For parametric data, continuous variables were demonstrated as mean±SD (standard deviation). Pearson-correlation used for the correlation between continuous parametric data.

4. Results

Table 2 shows that more than half (62.23%) of the patients were males and more than half (37.68%) of them aged between 40 to less than 50 years old. Nearly two thirds (66.67%) of the studied patients were resident from rural areas and more than two thirds of them were married. Concerning the educational level, more than half (55.07%) of the patients had basic education while 21.73% of them just read and write. For job, above one quarter (30.43%) of the studied patients were housewives or not, had any occupation while 26.08% of them had skilled work. In relation to income satisfaction, more than half (52.17%) of the studied patients didn't have enough income.

Table 3 reveals that nearly half (49.27%) of the studied patients had CKD from 3 years to less than 6 years, and

more than three quarters (75.37%) of them had co-morbid illnesses such as hypertension, diabetes mellitus and hepatic diseases. Regarding the mode of treatment, the majority (89.86%) of the studied patients were on maintenance hemodialysis treatment, while only 10.14% of them were on hemodialysis treatment and prepared for kidney transplantation.

Table 4 shows that there is a statistical significant difference of patients' QoL dimensions: physical function; role limitations due to physical problems; general health; and role limitations due to emotional problems/mental health between before and after implementing the self-management program (P. value < 0.05). There is also highly statistically significant difference of patients' QoL dimensions: social function and mental health/emotional well-being between before and after implementing the self-management program (P. value < 0.01) but there is no statistical significant difference of patients' QoL dimensions: pain and vitality/energy between before and after implementing the self-management program (P. value = 0.096 and 0.081 respectively).

Table 2. Distribution of the studied patients as regards their socio-demographic characteristics (n=69)

Socio-demographic characteristics		Number	%
Gender	Male	43	62.32
	Female	26	37.68
Age in years	18 – < 30	6	8.71
	30 – < 40	11	15.94
	40 – < 50	26	37.68
	50 – 60	17	24.63
	> 60	9	14.04
Residence	Rural	46	66.67
	Urban	23	33.33
Marital status	Single	13	18.84
	Married	49	71.01
	Divorced	5	7.25
	Widow	2	2.90
Educational level	Read & Write	15	21.73
	Basic education	38	55.07
	University	16	23.20
Occupation	Student	2	2.90
	Skilled worker	18	26.08
	Employee	16	23.20
	Housewife & No occupation	21	30.43
	Retired	12	17.39
Income satisfaction	Enough	7	10.15
	Not enough	36	52.17
	Not enough & Borrow	26	37.68

Table 3. Distribution of the studied patients as regards their clinical data (n=69)

Clinical Data		Number	%
Duration of illness	6 months – < 3 years	19	27.53
	3 years – 6 years	34	49.27
	> 6 years	16	23.20
Co-morbid illness	No co-morbid illness	17	24.63
	Co-morbid illnesses (Diabetes Mellitus, Hypertension, Hepatic Diseases, etc.)	52	75.37
Mode of treatment	Hemodialysis Treatment	62	89.86
	Preparation for transplantation	7	10.14

Table 4. Differences of QoL dimensions before and after the self-management program (n=69)

Dimensions of QoL	Before Mean ± SD	After Mean ± SD	t	P
Physical function	48.55±15.88	50.07±16.48	-2.294-	0.025*
Role limitations due to physical problems	31.15±25.51	35.71±24.92	-2.082-	0.041*
Pain	47.97±20.76	49.42±20.71	-1.689-	0.096
General health	45.57±22.22	47.1±21.66	-2.121-	0.038*
Vitality/ energy	39.34±24	40.5±24.43	-1.773-	0.081
Social function	44.02±22.13	51.81±19.20	-8.339-	0.000**
Mental health/emotional well-being	41.79±18.86	48.73±18.55	-8.596-	0.000**
Role limitations due to emotional problems/mental health	41.54±29.37	48.3±28.31	-2.574-	0.012*

(*) Statistically significant at p < 0.05
(**) Highly statistically significant at p < 0.01.

5. Discussion

Chronic Kidney Disease is not only a clinical concern, but also a growing economic and organizational problem. Quality of life is crucially significant for patients with CKD as they attempt to resignify the condition they face. Therefore, any intervention that may prevent the deterioration of their QoL is extremely important [19]. The current study aimed to evaluate the effect of the self-management program on QoL for patients with CKD.

According to the present study findings, the differences between before and after implementing the self-management program in terms of QoL domains: physical functions; role limitations due to physical problems; general health; role limitations due to emotional problems-mental health; social functions; and mental health-emotional well-being was statistically significant while there is no statistical significant difference of patients' QoL dimensions: pain and vitality/energy between before and after implementing the self-management program. These findings provide preliminary evidence on the effectiveness of self-management program on QoL of CKD patient.

Reasonable explanations for these results can be provided through a self-management program that helps the patients to manage the CKD symptoms, also to mange bio-psycho-social outcomes associated with CKD, and to make positive changes in life-style. Self-management of CKD includes focusing on personal needs regarding illness through gaining knowledge, skills to control symptoms, resources activation through recognizing and obtaining support and resource, and adaptation with the current conditions through identifying coping strategies with the situation and its effect on their lives and the emotional outcomes of the CKD. All of these factors most probably played an important role in improving QoL of CKD patients.

In addition, in the present research, patients learned various skills such as decision-making, problem solving, creation and development of cooperation with each other and with caregivers, stress management techniques, dealing with stress and emotional disturbances and utilization of health resources. In consequence, by mastering skills of self-management program, patients can manage and control physical implications associated with the disease and cope with psychosocial problems.

One of the most important techniques used in the self-management program is self-monitoring. By using self-monitoring skill, systematic observations, and recording of everyday emotions and activities, patients can recognize factors that lead to their psychosocial and problems. They have realized that some routines, thoughts and behaviors, such as consuming a salty or high-protein diet or distorted thoughts about their future, affect their physical and mental health status. When patients' health improves by organizing ideas and behaviors by identifying these factors, these positive feedbacks increase their confidence in managing their illness. Another advantage of the self-management program is the opportunity for patients to share their experiences, and to observe and learn indirectly from the successful models of other group members.

In the present study, QoL dimensions, pain and vitality/energy, had no significant difference after implementing the self-management program. Nonetheless, the scores of the two dimensions increased slightly after implementing the self-management program. This result indicated that pain and vitality/ energy were the least affected dimensions of QoL of patients with CKD. It might be due to the large burden on CKD patients undergoing hemodialysis who constituted the majority (89.86%) of the studied patients. It is known that the usual regime is 2 to 3 sessions per week, 4 to 6 hours for each session. In addition, prior researches reported that pain accounts for approximately 40% of the universe of complaints made by patients with CKD during hemodialysis, and many of these painful symptoms have a known physiopathological mechanism [20].

Constant with the present research is the study by Kuwaiti, Ghadami, and Yousefi [21] who reported that the implementation of the self-management program had a significant difference in the patients' QoL after the intervention and 3 months after the intervention and the score of the QoL in the experimental group compared with that of the control group had increased.

In addition, Novac, Costantini, Schneider and Beanlands [22] confirmed that CKD patient who became self-management expert is able to maximize the ability to cope with poor QoL and slow-down the deterioration of their health. In addition, a patient who has the potential ability to avoid the emergence of CKD outcomes achieves improved physical and psychological well-being and good QoL.

In addition, A systematic review by Mason, Khunti, Stone, Farooqi, and Carr [23] examined prior studies used randomized controlled trial method for the effect of a self-management program for CKD patients and revealed that most studies findings documented the potential effect of the self-management program regarding the experimental statistics, mental, behavior, and patients' knowledge and skills. In more recent meta-analysis, Lee et al. [9] reported that CKD self-management programs did effectively improve patients' mental quality of life but cannot improve patient's physical QoL.

By contrast, Ahmadzadeh, Matlabi, Allahverdipour, and Khodaei Ashan, [24] found that there wasn't statistically significant difference between general QoL pre and post the self-management program, scoring of all domains except emotional-mental health, demonstrated an increase after the intervention. This may be due to lack of literacy, lack of repetition, lack of continuous sessions, and inadequate study time.

6. Conclusion

To conclude, the current study revealed that the self-management program used in this research has a positive influence on preventing QoL deterioration among patients with CKD.

7. Recommendations

Health care providers should consider a holistic approach in treating patients with CKD. They should motivate patients to self-manage their disease to manage their stressors and to prevent the deterioration in their QoL.

Self-management programs will be useful if it is accompanied by other therapeutic and welfare actions and comprehensive supports of public and private charity organizations.

Acknowledgements

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