Effect of an Educational Intervention Based on Family-Centered Empowerment Model on Quality of Life of Hemodialysis Patients and Their Caregivers Hemmat Mostafa Al-agamy¹, Latifa Mahmoud Fouda ², Amaal Mohamed El Zeftway³, Neamat Mazloum Mohammed ⁴.

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Abstract

Background: Hemodialysis is a lifesaving chronic therapy for an increasing number of patients with end-stage renal disease (ESRD), and family caregivers of hemodialysis patients are the first and most crucial source of care at home. Aim of study: Evaluate the effect of an education intervention based on family-centered empowerment model on the quality of life of hemodialysis patient and their caregivers. Subjects and Method: Study design: Quasi-experimental design was used. Study setting: The study was conducted at dialysis unit at Tanta University Hospitals and Kafr El- Sheikh University Hospital. Study subjects: A random sample of 60 patients with chronic renal failure and their caregivers. Tools of data collection: For patients: - Tool I: - A structured questionnaire schedule was used to carry out this study, Tool II: Chronic Kidney Disease Self-Efficacy Instrument, Tool III: World Health Organization Quality of life-BREF. For caregivers:-Tool IV: A Structured interview schedule, Tool V: Scale of General Self-Efficacy for measuring Caregiver Self -Efficacy, Tool VI: Zarit Burden Interview, Tool VII: The Adult Carer Quality of Life Questionnaire Results: There was a significant improvement in total quality of life of the studied patients post implementation of intervention program with highly statistically significant difference at (P=<0.01) between pre, immediate and three months post of intervention program. There was improvement in overall quality of life of the studied caregivers as support of caring percentage (18.3%,56.7% and 50% respectively) in pre, immediate post and three months post intervention program. Conclusion: The educational intervention program based on family centered empowerment model was effective and quality of life of the studied hemodialysis patients and their caregivers were improved after implementation of the program. Furthermore, a significant improvement was observed in overall quality of life among the studied hemodialysis patients and their caregivers throughout the study phases. Recommendations: Educational intervention programs based on family centered empowerment model should be established in all hemodialysis units.

Keywords: Family-Centered Empowerment Model, Hemodialysis Patients, Quality of Life, Caregivers.

Introduction

Chronic renal failure (CRF) is a multidimensional public health problem that tends to become an epidemic and has a serious impact on the quality of patients' life. The quality of life is significantly associated with changes in daily habits and lifestyle for patients requiring dialysis and their families. At the same time, patients' physical health, functional status, personal relationships,

social and economic prosperity are greatly affected (1).

In united states 2017, there were 124,500 new cases of registered end stage of renal disease (ESRD), compared to 125,408 the prior year. The standardized rate of 340.7 per million in 2017 was the lowest since 1998. This likely reflects improvements in the prevention or postponement of kidney failure in the United States, possibly

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due to interventions such as greater blood pressure control and the use of statins in the general population. The prevalence of ESRD continues to rise and reached 746,557 cases in 2017(vs 727,912 in 2016), representing a 2.6% increase since2016, a reflection of decreasing mortality rates in the ESRD population (2).

In developing countries such as Egypt, according to Egyptian Renal Data System 1st Annual Report (2018), seventy-four dialysis units from 17 Egyptian governorates (cities) participated with their data in ERDS 2018 report with a 6,757 total number of patients and the most common cause of ESRD in Egypt in 2018 is hypertension (38%), followed by diabetes mellitus (18%). Patients with ESRD of unknown etiology represent the third common presentation (12%) ⁽³⁾.

End stage of renal disease (ESRD) has many causes and risk factors that vary from one patient to another. The key risk factors for chronic kidney disease (CKD) are the increasing age of the population, diabetes mellitus, hypertension and medications, such as the use of analgesics regularly over long durations of time resulting in analgesic nephropathy and kidney damage. Polycystic kidney disease is an example of a hereditary cause of CKD, Diabetes is the largest single cause of ESRD in the United Kingdom, accounting for 30-40% of all cases. In many Arab countries, obstructive uropathy constitutes a major cause of ESRD (40%). The two most common underlying causes of CKD are renal calculi and schistosomiasis. In many developing countries, chronic glomerulonephritis is often caused by infections and infestations, and is a leading cause of CKD (4).

Accurate assessment of quality of life among hemodialysis patients and adoption of effective interventions to improve quality of life among those patients are importance in terms of evaluating and improving the treatment process. According to, the definition provided by the World Health Organization (WHO), quality of life refers to individuals' perceptions of their positions in life in terms of culture,

value system in which they live in, goals, expectations, as well as standards and priorities ⁽⁵⁾. Nowadays, improving quality of life in patients receiving hemodialysis is considered as one of the most important therapeutic goals in the domain of working with this target group ⁽⁶⁾.

Dialysis population is becoming older and has an increased risk of physical, cognitive, and emotional deterioration, due to diabetes, hypertension, cardiovascular risk factors, multiple metabolic disturbances, pulmonary and skeletal problems. In addition, their mobility and ability to self-care being negatively affected. Thus, elderly dialysis patients need care not only from health professionals but also from caregivers, including spouses, parents, brothers and sisters, friends, as well as emotionally involved volunteers (7,8).

Family support has a positive effect on successful patients' adaptation to dialysis treatment and compliance with dietary regimen. However, sometimes patients discontinue dialysis treatment due to their perception that they have become a 'burden' to their family. Thus, family caregivers play a vital role in caring for older adults as well as the provision of effective communication to dialysis patients when it is appropriate. However, care giving is regarded as a chronic stressor due to the demanding activities and the emotional burden of caring ⁽⁹⁾.

The family-centered empowerment model (FCEM) is an Iranian model developed by Alhani, 2003 to prevent iron-deficiency anemia in adolescent girls. The model of family-centered empowerment consists of four phases. First phase: knowledge enhancement through educational sessions by using educational assistive materials such as power point, posters, model and handouts and educational methods as group discussion, question and answer and lecture. Second phase: self-efficacy enhancement; third phase increasing self-esteem through educational participation; and fourth phase including evaluation process during the empowerment sessions (10,11).

Nurses have an essential role in educating the family caregivers about coping strategies to increase caregivers' confidence and hope, which promotes family health and wellness. All family functions can be disturbed because of their concerning about patient's health care needs, medical and educational services, cost of the disease, missing social opportunities, frequent absences from work and physical and psychological problems. Therefore, participation of the patient in the care process alongside his/her family caregiver is very important (12).

Significance of the study:

Hemodialysis as a treatment for chronic kidney disease alter the patients' lifestyle, health status, and social roles. In the long term, the negative symptoms of hemodialysis therapy (such as pain, sleep disorder, depression) these factors reduce their living standards, cause physical and mental problems, and limit recreational, social, and occupational activities. Those patients are therefore in need of care and support.

So, the educational programs are essential to enable hemodialysis patients and their caregivers to care for themselves in the following domains: vascular access care, diet, fluid intake, medications, management of complications and psychosocial problems management (13). So, the aim of this study was to: Evaluate the effect of an education intervention based on family-centered empowerment model on the quality of life of hemodialysis patient and their caregivers.

Research hypothesis: Quality of life of the hemodialysis patients and their family caregivers are expected to be improved after implementation of an education intervention program based on family-centered empowerment model.

Subjects and Method

Subjects

Study design:

Quasi-experimental study design was utilized in this study.

Study settings:

Dialysis unit at Tanta University Hospitals and Kafr El- Sheikh University Hospital. Each unit of hemodialysis at Tanta University Hospitals and Kafr El-Sheikh University Hospital consists of 10- 13 hemodialysis (HD) active stations. On average, there were 20–25 HD patients dialyze each day. (Working in a three-shift system: morning, afternoon and night).

Study subjects:

A random sample of 60 patients with chronic renal failure and their caregivers (30 patients and their caregivers from Tanta university hospitals and 30 of them from Kafr El-Sheikh University Hospital). The sample calculation was done using EPi-Info software computer program software statistical package created by health world organization and center for disease control and prevention, Atlanta, Georgia, USA version 2002. The sample size was calculated at N > 56 based on the following criteria: 95%confidence limit, 80% power of study. The sample size was increased to be 60 patients with chronic renal failure and 60 caregivers (who provide care to the patient).

Tools of data collection:

In order to collect the necessary data, seven tools were used in this study (three tools for patients and four tools for caregivers).

A. Patient's tools:

Tool I: Structured interview schedule: this tool was developed by the researcher after reviewing the related literatures to collect the necessary data it consisted of two parts: -

Part 1: Socio demographic characteristics of the hemodialysis patients: It included data about age, sex, marital status, level of education, occupation, income and its source, and place of residence.

Part 2: Health history of the hemodialysis patients:

This part was included past and current health history of the patients as date of hospital admission, number and cause of previous hospitalization, history of chronic diseases and types of medication taken for it, history of kidney disease, onset, duration of disease, affected side, types of treatment, medication received, period for developing kidney failure, and number of hemodialysis sessions per week. Tool II: Chronic Kidney Disease Self-Efficacy Instrument (CKD-SE) (14)

This tool was used to assess patients 'selfefficacy to deal with the disease it was originally developed by Lin (2011) to assess the person confidence in his /her ability to overcome barrier in order to perform disease specific self-management behavior. It was adopted by the researcher in this study. The Chronic Kidney Disease Self-Efficacy (CKD-SE) instrument included a 25-item self-reported questionnaire. It consisted of four subscales: autonomy (eight items), self-integration (seven items), problem solving (six items) and seeking social support (four items). Scoring each item was rated on four point which was ranging from one (least relevant) to four (most relevant). The total score ranged from 25-100.

- Scoring system was categories as follows:
 - ➤ No self-efficacy:-< 25% of the total score.
 - ➤ Mild self-efficacy: $25\% \le 50\%$ of the total score.
 - ➤ Complete self-efficacy: >50% of the total score.

Tool III: World Health Organization Quality of life-BREF (WHOQOL-BREF) (15) WHOQOL-BREF was an abbreviated generic Quality of Life Scale developed by World Health Organization in the year 1997. It was adopted by the researcher in this study. The WHOQOL-BREF instrument comprised 26 items. The twenty-six standard items contained two generic items (over all QOL and general health) and remaining 24 items can be further classified into four domains:

- Physical domain (7 items).
- Psychological domain (6 items).
- Social relationship domain (3 items).
- Environmental domain (8 items).

The score ranged from 26-130. The score 26 referred to the worst possible QOL and the score 130 referred to the best possible QOL.

The scoring system of quality of life will be categorized as follows:

- 1. Poor quality of life: < 78 point (< 50%) of the total score.
- 2. Good quality of life: ≥ 78 point ($\geq 50\%$) of the total score.

Caregivers' tools included:

Tool IV: Structured interview schedule (16-18) It included socio-demographic characteristics of the patient's family caregivers such as: age, sex, marital status, occupation, level of education kin relation with the patient, number of children, health problems, other burden on family caregivers as other patient in family and the duration that he / she is offering care to the patient.

Tool V: Scale of General Self-Efficacy (GSE) for measuring Caregiver Self -Efficacy (19)

General self-efficacy (GSE): The SGSES (Sherer et al., 1982) was a Likert format 17-item scale (example of items include: "When I make plans, I am certain I can make them work ", "I give up easily ", "I am a self-reliant person ", "I avoid facing difficulties"). The response format was a 5-point scale (1 = strongly disagree, 5 = strongly agree). It was be adopted by the researcher in this study. Total possible scores ranged from 17 to 85, with a higher score was indicating a deeper belief in one's ability to succeed in performing one's duties.

Scoring system was categories as follows:

- ➤ No self-efficacy:-< 25% of the total score.
- ➤ Mild self-efficacy: $\ge 25\% \le 50\%$ of the total score.
- ➤ Complete self-efficacy: > 50% of the total score.

Tool VI: Zarit Burden Interview(ZBI)^(20,21):

This was used to assess burden of caregivers. It was originated as 29-item questionnaire by Zarit, Reever, Bach-Peterson, 1980⁽²⁸⁾. Then, it was revised and modified by Herbert et al. (2000) ⁽²⁹⁾ to contained 22 items such as (Do you feel that your relative asks for more help than he/she needs and Do you feel embarrassed over your relative's behavior?). It was adopted by the researcher in this study. Each item on the interview was a statement, which the caregiver was asked to endorse using a Likert 5-point scale. Response options ranged

from 0 (never) to 4 (nearly always). ZBI total score ranged from 0 to 88.

The burden of the caregivers was derived as follows:

- 1. Little or No burden \rightarrow from 0-20 points.
- 2. Mild burden \rightarrow from 21-40 points.
- 3. Moderate burden \rightarrow from 41-60 points.
- 4. Sever burden \rightarrow from 61-88 points.

Tool VII: The Adult Carer Quality of Life Ouestionnaire (22)

The Adult Carer Quality of Life Questionnaire (AC-QoL) developed by Elwick et al. (2010) and the AC-QoL Questionnaire was a simple instrument used with adult carers to measure their overall quality of life. it consisted of eight domains of quality of life: support for caring; caring choice; caring stress; money matters; personal growth; sense of value; ability to care; and carer satisfaction. It was adopted by the researcher in this study. Each domain consisted The AC-QoL Questionnaire of five items. consisted of 40 items that had a four-point Likert format that ranged from 0 (never), 1 (sometimes), 2 (A lot of the time), and 3 (always) for the following questionnaire items: (1-5), (17-18), (20-36), (39, 40)(never), 2 (sometimes), 1 (A lot of the time), and 0 (always) for the following questionnaire items: (6-16), 19, 37 & 38.

Scoring system of the Adult Carer Quality of Life Questionnaire: -

The total score was obtained by summing responses to each item of the questionnaire. Scores on the overall questionnaire had a possible range of 0 to 120 with higher scores were indicating greater quality of life. Total score was categorized as follows:

- ➤ The score 0-40 Indicated a low reported quality of life, and may suggest problem or difficulties.
- ➤ The score 41-80 Indicated a mid-range reported quality of life, and
- ➤ The score ≥81 Indicated a high reported quality of life

The scores on each of the eight subscales had a possible range of 0 to 15, with higher scores were indicating greater quality of life on that

subscale. Each domain was categorized as follows:

- ➤ The score 0-5 Indicated a low reported quality of life, and may suggest problems or difficulties,
- The score 6-10 indicated a mid-range reported quality of life on that subscale.
- ➤ The score ≥11 Indicated a high reported quality of life on that subscale

Method

1-Obtained approval:

An official permission to conduct the study was obtained from the Dean of the Faculty of Nursing to the manager of Tanta University Hospitals and Kafr El-Sheikh University Hospital and then to the Director of Hemodialysis Unit.

2-Ethical considerations:

The protocol of this study was approved -of from the faculty's ethical committee

- -An informed consent was obtained from all study participants after providing appropriate explanation about the purpose of the study.
- Each participant was informed that he/she has the right to withdraw from the study any time.
- -Confidentiality and privacy were put into consideration regarding the data collected.
- -Nature of the study wasn't led to any harm or pain for the entire subjects.

3-Developing tool:

Tool I for patients and their caregivers were developed by the researcher based on literature review. All tools for patients and their caregivers will be translated into Arabic language by the researcher.

4-Study tools were tested for its face and content by a jury of five-professor expertise in the field of Community Health Nursing and Medical – Surgical Nursing departments before conducting the study. Then necessary modifications were done.

5-Study tools were tested for its reliability by using Cronbach's alpha test, and found to be(0.931) for all the study tools, for tool I:-Socio demographic characteristics of the hemodialysis patients and Health history of the hemodialysis patients = (0.888), for Chronic Kidney Disease Self-Efficacy Instrument (CKD-SE) = (0.867), for World Health

Organization Quality of life-BREF= (0.899), and for Structured interview schedule of caregivers= (0.913) ,for part Scale of General Self-Efficacy (GSE) for measuring caregiver self –efficacy= (0.809) ,and for Zarit Burden Interview(ZBI) = (0.814), finally for The Adult Carer Quality of Life Questionnaire = (0.701).

- 6- A pilot study was carried out on 10% of the total sample after taking their approval to test the tool for its clarity, organization, determine length of time needed to collect this data. The necessary modifications were done, and those patients and their caregivers were excluded from the actual study subjects.
- **7-The researcher met with** nearly 12 patients with their caregivers per day two times weekly at hemodialysis unit.
- **8-The duration for collecting the data** started from January to November 2020.
- **9- Developing the educational intervention**: This was included the following phases:
- **a.** Assessment phase: The data was collected by the previously mentioned tools through interviewing each hemodialysis patient and his/her caregiver individually in predetermined setting to collect the baseline data as a pre-intervention assessment.
- b. Planning phase: The education intervention was planned according to hemodialysis patient and their caregiver's needs obtained from the assessment phase and through literature review.

The goal of the education intervention was to empower the hemodialysis patients and their caregivers to gain knowledge and skills and enable them to cope with the sequences of hemodialysis for improving their quality of life.

Objectives of the program: At the end of the educational intervention the participants were able to:

- Explain indications of hemodialysis.
- Describe consequences of hemodialysis sessions.
- Discus nutritional needs of hemodialysis patient.

- Measures for managing stressful situations.
- Explain to the caregivers how to prepare the patients psychologically for hemodialysis sessions
- Demonstrate and re-demonstrate muscle relaxation exercises for HD patient and their caregivers.
- Apply the proper problem solving technique to overcome needs of patients and their caregivers.
- c) Implementation phase: The education intervention-based family- centered empowerment model sessions were 5 sessions. The duration of each session was ranged from 45-60 minutes.

The sessions were as follow:

Session (1): The aim of this session was to orient the HD patients and their family caregivers about the importance of the program, its session and to assess their program expectation from each session

Session (2): The aim of this session was to increase the HD patients and their family caregiver's knowledge about definition, indications of HD, preparation before session of HD, nutrition needs of patients with HD, consequences of hemodialysis sessions and methods of measuring weight, height, and blood pressure.

Session (3): The aim of this session was to improve HD patient and their family caregivers' problem-solving technique.

Session (4): The aim of this session was to improve HD patient and their family caregivers how can manage stressful situations.

Session (5): The aim of this session was to apply muscle relaxation exercise for HD patient and their family caregivers.

-The following methods and materials were used for implementation of educational intervention: Lectures, discussions, demonstration, and re-demonstration were used as teaching methods. Power point presentation, pictures, videos and handouts like (colored booklet and brochure) were used as teaching aids.

D) Evaluation phase: Evaluate the effectiveness of the empowerment intervention program on quality of life of the HD patients and their caregivers.

First time (pretest): - Before implementation of the empowerment intervention, (using the seven study Tools).

Second time (immediate posttest): - Immediate posttest of implementation of the empowerment intervention by using (tool II & III for the patient and tool V and VI&VII for the caregivers).

Third time (post - test): After three-months from the implementation of the empowerment intervention program, (using tool II & III for the patient and tool V and VI&VII for the caregivers).

10- Statistical analysis:

The statistical analysis of data was done by using the computer software of Microsoft Excel Program and Statistical Package for Social Science (SPSS) version 22. Statistical methods were applied including descriptive statistics such as (frequency, percentage, mean (X) and standard deviation (SD). Chi-square test analyzes the differences. P-values were considered statistically significant when:

- P-value > 0.05 Not significant (NS)
- P-value ≤ 0.05 Significant (S)
- P-value \leq 0.01 Highly Significant (HS).

Results

Table (I): represents the distribution of the studied patients according to their socio demographic characteristics. The table shows that, more than half (58.3%) of the studied patients their age were ≥ 50 year with a mean of 51.3 ± 6.15 year. As regards to sex and marital status, more than two-thirds of them (68.3% and 70% respectively) were male and married. Concerning to occupational and education level the table reveals that three- quarters (75%) of the studied patients were not working / housewife, and more than half of them, (56.7%) had secondary / technical education. In relation to income half of them (50%, 50%) mentioned that their monthly income was not

enough and brow, and their income from pension respectively. Meanwhile, slightly less than two thirds (63.3%) of them were living in rural areas.

Table (II): Represents mean score of the studied hemodialysis patients throughout the study phases regarding to their self-efficacy to deal with the disease. The table shows that, the mean score and standard deviation of autonomy increased from17.97±4.15 pre an educational intervention program to 25.05±0.98 immediate post an education intervention program and 21.90±1.02 three months post educational intervention program, also hemodialysis patient self-integration improved from 19.31±3.74 pre an educational intervention program to 24.71±0.90 immediate post an educational intervention program and 22.37±1.21 three months post educational intervention program. Regarding to problem solving increased from 16.91±3.22 pre an educational intervention program to 21.57±1.08 immediate post an educational intervention and 19.45±1.30 three months post education intervention program, also seeking social support improved from 9.33±4.04 pre an education intervention program to 14.60±0.88 immediate post an education intervention program and 13.73±0.99 three months post education intervention program. Finally, there was a marked improvement in the mean score of total selfefficacy of the studied hemodialysis patients post implementation of an educational intervention program and three months post from (63.52±15.15 to (85.93±3.84, 77.45±4.52 respectively) with highly statistically significant difference at (P= < 0.01) between pre, immediate and three months post of an educational intervention program.

Table (III): Represents the mean score and standard deviation of the studied hemodialysis patients throughout the study phases regarding to their overall quality of life. the table shows that, the mean score of physical health domain increased from15.32±3.75 pre an educational intervention program to 30.24±0.93 immediate post an educational intervention program and 28.94±1.10 three months post an educational intervention program. As regard to psychological health increased from 11.71 ± 4.30 pre an educational intervention program to 26.70±1.03 immediate post an education intervention program and 25.07±1.19 three months post education intervention program. The table also reveals that social relation improved from 5.67±3.72 pre an educational intervention

program to 13.47±0.98 immediate post educational intervention program and 11.95 ± 1.01 three months post education intervention program. environmental domain improved from 15.36±4.04 pre-educational intervention program to 34.69±0.99 immediate post education intervention program and 33.93±1.09 post education three months intervention program. Finally, there was a marked improvement in total quality of life of the studied patients post implementation of educational intervention program with highly statistically significant difference at (P = < 0.01) between pre, immediate and three months post of educational intervention program.

Table (IV): represents the distribution of the studied patient's family caregivers according to their socio-demographic characteristics. This table reveals that slightly more than half (51.7%) of the studied caregiver their age was 20-<30 year with a mean of 32.9 ± 0.95 year. Concerning to sex and marital status the majority (80%) of them were male, while more than half (53.3%) of them were married. Also, slightly more than two - thirds (71.7%) of them were working. Regarding to educational level, more than half (53.3%) of them had secondary / technical education, and slightly less than half (46.7%) of the studied caregiver was daughter / son. Moreover, more than half (52.4%) of them had one child. Meanwhile, the majority (86.7%, 80% respectively) of them didn't suffer from any health problems, didn't had another patient in the family who can take care of him.

Table (V): Illustrates the distribution of the studied caregivers throughout the study phases regarding to their levels self-efficacy. The table shows that more than, half (56.6%) of the studied caregivers had complete self-efficacy immediate implementation of an educational intervention program and more than one-third (36.7% and 38.3% respectively) had a mild self-efficacy immediate and three months post an educational intervention program. Also, there was a marked improvement in the levels of self-efficacy of the studied caregiver post implementation of an educational intervention program with highly statistically significant difference at (p=< 0.01) between pre, immediate and three months post intervention program.

Table (VI): Represent the distribution of the studied caregivers through the study phases regarding to their levels burden. This table shows that, half (50%) of the studied caregiver had moderate burden at pre implementation of intervention program. While, more than half (55%) about more than one- third (48.4%) of them had a mild burden in immediate post and after three months post intervention program, Also, there was a marked decreased in the levels of burden of the studied caregivers immediate post intervention program with a highly statistically significant difference during pre, immediate post and three months post intervention program at (P= < 0.01).

Table (VII): Represents the disruptions of the studied caregivers throughout the study phases regarding to their overall quality of life for adult carers. This table illustrates that, there was improvement in overall quality of life of the studied caregivers as support of caring percentage (18.3%, 56.7% and 50% respectively) in pre, immediate post an educational and three months post an educational intervention program. Also, percentage of ability of care improved (26.7%, 55% and 50 respectively) in pre, immediate post an educational and three months post an educational intervention program. On other hand, the total mean score of overall quality of life improved from 78.34±7.10 in pre an educational intervention program to 101.04±0.97 immediate post an educational and 92.55±3.23 three months post an educational intervention program. Finally, this table illustrates that, there was a marked improvement in overall quality of life of the studied caregivers post intervention program with a highly statistically significant difference in pre, immediate post an educational and three months post an educational intervention program (P = < 0.01).

Table (VIII): Represents the correlation between total score of self-efficacy of the studied caregivers and their total score of burden and overall quality of life for adult carers at three months post of an education intervention program. This table presents that, there was a positive correlation between total score self-efficacy of the studied caregivers and their total score of burden and overall quality of life for adult carers at post intervention program at (P = < 0.000).

Table (1): Distribution of the studied hemodialysis patients according to their socio-

demographic characteristics

demographic characteristics							
Socio-demographic characteristics of hemodialysis patients	The studied hemodialysis patients (n=60)						
Age in years	No	%					
20-<30	5	8.3					
30-<40	7	11.7					
40-<50	13	21.7					
≥50	35	58.3					
Range 39							
Mean \pm S.D 51.3 \pm 6.15							
Sex							
Male	41	68.3					
Female	19	31.7					
Marital status	-						
Single	8	13.3					
Married	42	70					
Widow	6	10					
Divorced	4	6.7					
Occupation	1 7	0.7					
Not working / housewife	45	75					
Working:	15	25					
Type of work (n=15)	10	23					
Professional Work	8	53.4					
Handicraft	2	13.3					
Manual Work	3	20					
• Farmer	2	13.3					
Educational level		13.3					
Illiterate / read and write	8	13.3					
Elementary education	14	23.3					
Secondary / technical education	34	56.7					
University education / postgraduate	4	6.7					
Monthly income	1 4	0.7					
Enough and save	6	10					
Enough Enough	24	40					
Not enough and brow	30	50					
Source of income] 50] 30					
Monthly salary	12	20					
Charitable Associations	8	13.3					
Pension	30	50					
Property and land	6	10					
Family subsidies	4	6.7					
Place of residence	T -	0.7					
Rural	38	63.3					
Urban	22	36.7					
OTOGII	44	30.7					

Table (II): Mean score and standard deviation of the studied hemodialysis patients throughout the study phases regarding to their self-efficacy to deal with the disease

	The studied hemodialysis patients										
(n=60)											
Self-efficacy	Pre- an education intervention program	Immediate post- an education intervention program	Three months post intervention program	χ ₂ P							
	Mean SD	Mean SD	Mean SD								
Autonomy	17.97±4.15	25.05±0.98	21.90±1.02	27.80 .000**							
Self-integration	19.31±3.74	24.71±0.90	22.37±1.21	29.50 .000**							
Problem solving	16.91±3.22	21.57±1.08	19.45±1.30	25.70 .001**							
Seeking social support	9.33±4.04	14.60±0.88	13.73±0.99	28.57 .000**							
Total self-efficacy	63.52±15.15	85.93±3.84	77.45±4.52	27.92 .000**							

^{*}Significant at p <0.05. **Highly significant at p <0.01.

Table (III): Mean score and standard deviation of the studied hemodialysis patients throughout the study phases regarding to their overall quality of life

The studied hemodialysis patients (n=60)									
Domains of quality of life	Pre- an education intervention program Immediate post- an education intervention program Follow up of education intervention program			χ² P					
	Mean SD ±	Mean SD ±	Mean SD ±	·					
Overall health quality of life	2.07±1.30	7.91±2.67	6.61±3.14	21.31 .000**					
Physical health	15.32±3.75	30.24±0.93	28.94±1.10	22.17 .001**					
Psychological health	11.71±4.30	26.70±1.03	25.07±1.19	24.82 .000**					
Social relationship	5.67±3.72	13.47±0.98	11.95±1.01	25.12 .000**					
Environmental	15.36±4.04	34.69±0.99	33.93±1.09	20.14 .002**					
Total quality of life	48.06±15.81	105.1±3.93	99.89±4.03	23.69 .000**					

^{*}Significant at p $\langle 0.05.$ **Highly significant at p $\langle 0.01.$

Table (IV): Distribution of the studied caregiver according to their socio -demographic characteristics

socio -demographic characteristics of the studied patient's family caregivers n=(60)	No	%
Age (Year)		<u>_</u>
20-<30	31	51.7
30-<40	18	30
40-<50	7	11.6
>50	4	6.7
Range 31		•
Mean \pm S.D 32.9 \pm 0.95		
Sex		
Male	48	80
Female	12	20
Marital status		
Single	18	30
Married	32	53.3
Widow	6	10
Divorced	4	6.7
Occupation		0.7
Not working / housewife	17	28.3
Working	43	71.7
Educational level	1.5	, 2.,
Illiterate / Read and write	6	10
Elementary education	14	23.3
Secondary / technical education	32	53.3
University education / postgraduate	8	13.3
The degree of kinship with a hemodialysis patient		1 2010
Wife / Husband	17	28.3
Brother / Sister	9	15
Daughter / Son	28	46.7
Father / Mother	6	10
The number of children (n=42)		
Child	22	52.4
Two children	12	28.6
Three or more children	8	19
Suffer from any health problems:-		I.
Yes	8	13.3
No	52	86.7
If yes, what are they (n=8)		
Hypertension	5	62.5
Diabetes mellitus	3	37.5
Another patient in the family who can take care of him		•
Yes	12	20
No	48	80
If yes, how long do you care for him (n=12)		
< 5 years	8	66.7
≥ 5 years	4	33.3

Table (V): Distribution of the studied caregiver throughout all the study phases regarding to their levels of general self-efficacy

Levels of self-efficacy	interv	The s	χ ₂ P				
	No	gram 0/0	No	gram %		ention gram	
No self-efficacy	13	21.7	4	6.7	7	11.7	24.31
Mild self-efficacy	31	51.7	22	36.7	23	38.3	.000**
Complete self-efficacy	16	26.6	34	56.6	30	50	

^{*}Significant at p <0.05. **Highly significant at p <0.01.

Table (VI): Disruption of the studied caregivers throughout the study phases regarding to their levels of burden

the studied patient's family caregivers n=(60)									
Levels of the caregivers burden	interv prog	Pre intervention program (n=60) Immediate post intervention program (n=60)			post int pro	months ervention gram =60)	χ ² P		
	N	%	N	%	N	%			
Little or No burden	2	3.3	10	16.7	8	13.3	23.60		
Mild burden	8	13.3	33	55	29	48.4	.000**		
Moderate burden	30	50	12	20	14	23.3			
Severe burden	20	33.4	5	8.3	9	15			
Mean SD	74.8±4	.13	44.3±1.07		59.4±1.0	64	23.60		
							.000**		

^{*}Significant at p <0.05. **Highly significant at p <0.01.

Table (VII): Distribution of the studied caregivers throughout the study phases regarding to their overall quality of life for adult carers

the studied patient's family caregivers n=(60)																			
Overall quality of	Pre- intervention program Immediate post intervention program				onths pro	χ ₂ P													
life for adult	L	ow	M	ild	hi	gh	Lo	ow	M	ild	Hi	igh	Lo	OW	M	ild	I	ligh	
carers	No	%	No	%	No	%	No	%	No	%	No	%	No	%	No	%	No	%	
Support of caring	10	16.7	39	65	11	18.3	4	6.7	22	36.7	34	56.7	6	10	24	40	30	50	22.97 .000**
Caring choice	18	30	36	60	6	10	8	13.3	25	41.7	22	36.7	10	16.7	30	50	20	33.3	24.30 .000**
Caring stress	20	33.3	34	56.7	6	10	10	16.7	27	45	23	38.3	13	21.7	28	46.7	19	31.7	26.31 .000**
Money matters	15	25	35	58.3	10	16.7	7	11.7	32	53.3	21	35	8	13.3	30	50	22	36.7	22.39 .000**
Personal growth	12	20	34	56.7	14	23.3	8	13.3	22	13.3	30	50	10	16.7	20	33.3	30	50	25.14 .000**
Sense of value	10	16.7	30	50	20	33.3	5	8.3	24	40	31	51.7	7	11.7	32	53.3	21	35	19.99 .000**
Ability of care	14	23.3	33	55	13	26.7	7	11.7	20	33.3	33	55	9	15	21	35	30	50	21.36 .000**
Carer satisfaction	15	25	32	53.3	13	26.7	5	8.3	22	36.7	33	55	8	13.3	28	46.7	24	40	25.50 .000**
Overall quality of	15	25	34	56.7	11	18.3	7	11.7	24	40	29	48.3	9	15	25	41.7	26	43.3	24.55 .000**
life for adult carers			Mean /8.34±			Mean SD Mean SD 101.04±0.97 92.55±3.23													

Table (VIII): Correlation between total score of self-efficacy of the studied caregivers and their total burden and overall quality of life for adult carers at three months post intervention program

Variables	Total Self-Efficacy	Total Burden	Overall quality of life for adult carers
Total Self-Efficacy		r = 0.364 P = .002**	r = 0.345 P = .001**
Total Burden			r = 0.398 P = .000**

^{*}Significant at p <0.05. **Highly significant at p <0.01.

Discussion

Patients suffering from chronic kidney failure depend on family caregivers for routine tasks. The caregivers of patients with hemodialysis face a various difficulties and problems, including frequent hospitalization and multiple drug administration to the patients. Previous study showed that the availability of the patient's spouse or other family members improve his/her quality of life (23).

As regards to age, marital status and sex of the studied patients the result of current study revealed that more than half of the studied patients their age were ≥ 50 year with a mean of 51.3 ± 6.15 year, more than two thirds of them were married and more than two-thirds of the study patients were male (Table 1). This result goes in the same line with Darvishi et al. (2020) who conducted a study on twenty-four participants in Iran to determine effectiveness of spiritual therapy on spiritual well-being, self-esteem and self-efficacy in patients on hemodialysis and found that exactly one half of the studied patients aged 51-60 years and also two thirds of them were married

Also, the study conducted with Fei Xiong et al. (2020) in china on 7154 patients undergoing hemodialysis to observe clinical characteristics of and medical interventions for COVID-19 in Hemodialysis patients found that the mean age of the patients was 63.2 years and that more than half of the study participant were males (25). This result is in comparable with **Kauric**-Klein et al. (2017) who carried out a study in UUSA on118 participants to examine the effects of an educative, self-regulation intervention on blood pressure self-efficacy, self-care outcomes, and blood pressure control in adults receiving hemodialysis and found that more than one half of the study participant were males (26). These findings may be related to increase prevalence of kidney failure among old age above 50 years also, rely too difference in the number and personal characteristics

between participants in the two studies. Concerning to the occupational and education level of the studied subjects, the result of the current study showed that three- quarters of the studied patients were not working / housewife, and more than half of them had secondary / technical education (Table 1). This finding matched with the study done by Almutary et al. (2021) in Saudi Arabia 190 patients undergoing dialysis to evaluate self-efficacy among patients undergoing dialysis therapy and found that more than half of them had High School / technical education and the majority were not working (27). This may be due to differences in residence and in culture and norms between the two countries.

Concerning the distribution of the studied hemodialysis patients throughout the study phases regarding to their self-efficacy, the results of the current study illustrated that there was a marked improvement in total selfefficacy of the studied hemodialysis patients post implementation of an educational intervention program with highly statistically significant difference at (P = < 0.01) between pre, immediate and three months post of an educational intervention program (Table II) .This result is agreement with the study done by Lee et al. (2021) in Taiwan to evaluate Effectiveness of a self-management program in enhancing quality of life, self-care, and selfefficacy in patients with hemodialysis found that The program also promoted patients' selfcare behaviors and self-efficacy three months after the intervention (28). Also, the study done by Bayoumy et al. (2017) in Saudi Arabia to evaluate the efficacy of an empowerment Program for end-stage renal disease patients treated with hemodialysis found that patients' self-care behaviors and self-efficacy improved after program⁽²⁹⁾. These findings may be due to the application of self- efficacy items, and it shown a successful function of the patient as well as increase adherence to recommended care protocol.

The results of the current study revealed that, there was a marked improvement in overall quality of life of the studied patients post implementation of an education intervention program with a highly statistically difference at (P=<0.01) between pre, immediate and three months post an educational intervention program (TableIII).

This findings completely goes in the same line with the study applied by Fadlalmola and Elkareem (2020) in Khartoum on hemodialysis patients to evaluate the effectiveness of an educational program on the knowledge and quality of life among hemodialysis patients in Khartoum state and found that that there was a significant increase in the overall mean knowledge from 48.6% pre-intervention to 86.3% post-intervention of the program, thus improving the quality of life after its implementation specifically, the results revealed that there was a significant improvement in all domains of quality of life⁽³⁰⁾. Also, another study done by **Aghakhani** et al. (2018) in Iran to evaluate the self-care education at home impression on the quality of life in HD patients and found that that there was increase in the overall mean knowledge from 43.9% pre-intervention to 53.77% postintervention of the program (31). From the researcher point of view the educational programs considered to be a very effective method in improving quality of life for hemodialysis patients through increasing patient's awareness and knowledge about all domains in quality of life and lifestyle modification.

As regards to sex, marital status and age of the studied caregivers the result of the current study discovered that the majority of the study participants were male, while more than half of them were married and age was 20-<30 year with a mean of 32.9 ± 0.95 year (Table IV). This finding to some degree matched with the study done by Farzi et al. (2019) on 254 caregivers for hemodialysis patient in Isfahan to investigate the care burden and quality of life

in family caregivers of hemodialysis patients and their relationship with some characteristics of caregivers and patients and found that more than two thirds of the study participants were males and the majority of them were married ⁽³²⁾. These findings may be due to setting differences between the two studies.

As regards to the degree of kinship with a hemodialysis patients, educational level and occupation of the studied caregivers the result of the current study illustrated that slightly less than half of the studied caregiver were daughter / son, more than half of studied caregivers had secondary / technical education and slightly more than two - thirds of the studied caregivers were working (Table IV). This finding matched with the study done by Nataatmadja et al. (2021) in Australia to identify quality of life in Caregivers of patients randomized to standard- versus extended-hours hemodialysis and found that slightly less than half of the studied caregiver was secondary / technical education (33). also the study done by Syahri et al. (2020)) in Indonesia to identify caregiver burden associated-risk factor of chronic kidney disease patients with hemodialysis found that slightly less than half of the studied caregiver were son and slightly less than two thirds of them were working $^{(34)}$. while This finding not matched with the study done by Alnazly, (2018) in Amman, Jordan on 169 participants to identify caregivers' level of burden and establish the impact of educational intervention programs on caregiving outcomes and found that slightly less than one half of the studied caregiver was in the fourth years college (35). These findings can be justified to the setting difference, culture and norms between the participants of the two studies.

Concerning to the distribution of the studied caregiver through the study phases related to their self-efficacy, the results of the current study demonstrated that there was a marked improvement in caregivers' self-efficacy as when they set important goals for themselves, they achieve them and they didn't give up on

things before completing them there was a marked improvement in caregivers' self-efficacy as when they expected problem occur, they handle them well and they didn't give up easily post implementation of an education intervention program post implementation of an educational intervention program with highly statistically significant difference at (P=<0.01) between pre, immediate and three months post implementation of an educational intervention program (Table V).

This finding is supported by Rabiei et al. (2020) who found that there was no significant difference in the mean scores of care burden of positive outcomes expectancies, negative outcomes expectancies, and self-efficacy between the two groups before the intervention. However, there was a significant difference in the post-test and follow-up data analyses at (P=<0.05) (1). Furthermore, a study done by Hovadick et al. (2021) who carried out a study to evaluate the interventions to improve the well-being of family caregivers of patients on hemodialysis and peritoneal dialysis: systematic review and found that there was significant improvement in the caregiver's well-being and self-efficacy post session of intervention ⁽³⁶⁾. These findings may be due to the implementation an empowerment program, improved the patient's caregivers' behaviors and increased the positive outcomes expectancies.

This result was congruent with the finding of a study done by **Saiednejad et al. (2018)** in Kashan on 60 participants to determine the effectiveness of empowerment program based on the BASNEF model on the self-efficacy of patients under hemodialysis and found the total scores of the self-efficacy were increased after intervention (P < 0.002), In addition, significant difference was observed between the mean score of self-efficacy in the intervention group prior to and after the empowerment program (P < 0.0001), while no significant change was observed in the control group, before and after the study at (P = 0.17) (37). Also, a study done

by El-Melegy et al. (2016) in Egypt to evaluate the effect of family centered empowerment model on hemodialysis patients and their caregivers and found the a significant improvement in all self-efficacy categories for the majority of the studied subjects post empowerment intervention⁽¹⁸⁾. This improvement of self-efficacy can be characterized the features of participation of family members and health care givers in the problem-solving process. From the researcher point of view, these findings may be due to that participation of the patients' family in the empowerment program led to improvement of self-efficacy, quality of life, and general health of hemodialysis patients and this the outcomes of the intervention program.

According to distribution of the studied caregivers throughout the study phases regarding to their burden levels. The results of the current study showed that half of the studied caregiver had moderate burden at pre implementation of intervention program. While more than half and about more than one- third of them had mild burden in immediate post and after three months post intervention program. Also, there was a marked decreased in the levels of burden of the studied caregivers during immediate post intervention program with a highly statistically significant difference during pre, immediate post and three months post intervention program at (P=<0.01) (Table VI).

This result of the current study is consistent with the finding of a study done by Nagarathnam et al. (2019) in India on 90 caregivers to comparatively evaluate the burden, coping mechanisms, and QOL among caregivers of HD and PD undergoing and RT patients and found that less than one half of the studied caregivers had moderate burden in post intervention with a highly statistically significant difference at $(P < 0.01)^{(38)}$. Also, there was a study done by Mashayekhi et al. (2015) to assessment of caregiver burden in caregivers of hemodialysis patients that found half of the caregivers more than hemodialysis patients had moderate to severe levels of caregiver burden (39). These findings

may be related to difference between the two studies participants in relation to education, gender, religion, economic and cultural factors that may effect on caregivers coping, adaptation and tolerance to caregiving burden.

As regards to disruptions of the studied caregivers throughout the study phases related to their overall quality of life for adult careers, the results of the current study revealed that there was a marked improvement in overall quality of life of the studied caregivers post intervention program with a highly statistically significant difference in pre, immediate and three months post an educational intervention program (P = < 0.01) (**Table VII**) . This finding is consistent with the finding of a study done by Ghane et al. (2017) in Tehran, Iran on 76 family caregivers of hemodialysis patients to examine the effects of supportive educative program on the quality of life in family caregivers of hemodialysis patients and found that the mean scores of quality of life of the intervention group increased at the end of the study, and the two groups were significantly different in this regard at $(P < 0.001)^{(40)}$. Also, a study done by Ibrahim et al. (2020) in Egypt to evaluate the impact of health education program on health related quality of life among patients with end stage renal disease on hemodialysis and their caregivers at Ain Shams university hospital found that there were statistically significant increases in intervention group of the caregivers than the control group in social function, emotional well-being, role emotional and component summary scores⁽⁴¹⁾. From the researcher point of view, this finding may be attributed to training of caregivers and providing them with information about chronic renal failure, hemodialysis, its complications, and how to take care of patients at home that help in improve their quality of life, In addition to, learning how to take care of patients, coping skills that help them ease tensions, comply with their caring role, and promote mental health. These similarities in findings may be related to setting similarities and socio-demographic

characteristics as the two studies carried out in Egypt.

Concerning to the correlation between the total score of self-efficacy of the studied caregivers and their total score of burden and overall quality of life for adult carers at three months post education intervention program, the results of the current study illustrated that there was a positive correlation between the total of score self-efficacy for the studied caregiver and their total score of burden and overall quality of life for adult careers at post intervention program at (P=<0.000) (Table VIII). This result is in contrast with Pungchompoo et al. (2020) who conduct a study in Chiang Mai, Thailand on 41 participants to implement a repeated-measures experimental design to assess the effectiveness of a self-management retraining program and found that participants showed that there was a statistically significant increases in selfmanagement behavior (medical adherence) and mental health status. Perceived self-efficacy in self-management was improved and healthrelated quality of life; however, this change did not reach statistical significance (42). These differences in findings may be related to difference in setting and socio-demographic characteristics of the participants in the two studies

While similar a study conducted by Zhang et al. (2021) to evaluate the association between exercise self-efficacy and health-related quality of life among dialysis patients: a cross-sectional study and found that positive association was observed between exercise self-efficacy and health-related quality of life among $(r = 0.310, P < 0.001)^{(43)}$.

Hemodialysis affected negatively on physical, psychological, cognitive and social status of the patients and their caregivers and need a comprehensive approach of educational intervention program. Patients and their caregivers should be included and encouraged to participate actively in the care process. family centered empowerment model should be

directed toward increasing knowledge, awareness, and developing self-efficacy, self-esteem and self-control support adopting preventive behaviors and increases self-care self-efficacy of hemodialysis patients and their caregivers and relieving burden level upon caregivers.

Conclusion:

Based on the findings of the present study; it can be concluded that, the educational intervention program based on family centered empowerment model was effective and quality of life of the studied hemodialysis patients and their caregivers were improved after implementation of the program .

Furthermore, a significant improvement was observed in overall quality of life among the studied hemodialysis patients and their caregivers throughout the study phases. Moreover, there was a marked decreased in caregivers' burden and marked improvement in the levels of self-efficacy of the studied caregivers post implementation of intervention program than the preprogram.

Recommendations

In the light of results of this study, the following recommendations were suggested:

- Educational intervention programs based on family centered empowerment model should be established in all hemodialysis units for all hemodialysis patients and their caregivers to improve their quality of life and reduce complications.
- Written instructions about hemodialysis in the form of booklet or brochures should be provided to all patients and their family caregivers at all hemodialysis units.
- 3. Public health sectors should establish awareness campaigns directed to high-risk group for hemodialysis to improve their knowledge regarding end stage of renal disease ESRD.
- 4. In service continuous education programs should be planned by the staff of faculty of nursing and offered a regular basis to the nurses at all hemodialysis units. The program should include knowledge and practices of the personal case management of end stage of renal

disease (ESRD) patients recommended for hemodialysis.

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