Educational Administration: Theory and Practice
2024, 30(11), 1466-1474
ISSN: 2148-2403
https://kuey.net/

Research Article

"Assess Quality Of Life Of Caregiver Of Patients Undergoing Hemodialysis Among Selected Hospitals."

Mrs. Manisha Rahul Padekar[1*], Dr. Sujata Sawant[2], Ms. Sanjana Lokhande[3], Ms. Priyanka Kokate[4], Mr. Krushna Avhad[5]

[1*] Clinical Instructor, Dr. D. Y. Patil Institute of Nursing Education Pimpri, Pune.
[2] Principal, Dr. D. Y. Patil Institute of Nursing Education Pimpri, Pune.
[3] TY GNM Student of Dr. D. Y. Patil Institute of Nursing Education, Pune.

***Corresponding Author:** Mrs. Manisha Rahul Padekar
*Clinical Instructor, Dr. D. Y. Patil Institute of Nursing Education Pimpri, Pune.

Citation: Mrs. Manisha Rahul Padekar, et.al (2024). "Assess Quality Of Life Of Caregiver Of Patients Undergoing Hemodialysis Among Selected Hospitals.", *Educational Administration: Theory and Practice*, 30(11) 1466-1474
Doi: 10.53555/kuey.v30i11.9518

ARTICLE INFO

ABSTRACT

"A study to assess quality of life of caregiver of patients undergoing hemodialysis among selected hospitals."

AIM OF THE STUDY: To assess the quality of life of caregivers of patients undergoing hemodialysis.

RESEARCH METHODOLOGY: This study used a quantitative and descriptive research approach. The focus is on the Quality of Life of caregivers of patients undergoing hemodialysis. The research involved caregivers from selected hospitals, with a random sample of 120 first-degree relatives aged 18 to 65. Consent was obtained, and a structured questionnaire with a caregiver burden scale was used to assess quality of life, featuring demographic questions and response options like never, rarely, sometimes, and always. The tool showed high reliability. Data was collected and analysed using inferential and differential statistics.

RESULT: Data analysis related to Quality of life of caregivers of patients undergoing hemodialysis showed that the 36.7% (44) of the caregivers of patients undergoing hemodialysis had little or no burden, 30% (36) of them had mild burden, 29.2% (35) of them had moderate burden and 4.2% (5) of them had severe burden and none of the demographic variables were found to have a significant association with the quality of life among caregivers of patients undergoing hemodialysis.

CONCLUSION: The conclusion drawn from the findings of the study is that, caregivers of hemodialysis patients often experience reduced quality of life due to significant responsibilities, influenced by dialysis type and medication costs.

Keywords: Assess, Quality of life, Caregiver, Patients, Hemodialysis.

INTRODUCTION:

In India, an estimated 7.85 million people suffer from chronic kidney disease (CKD). CKD, also known as end-stage renal disease (ESRD), is a chronic and complex condition that affects the physical and mental well-being of the patient. Hemodialysis is the common treatment for ESRD. Hemodialysis causes a lot of physical and psychosocial stress, challenging not only the patient but also the caregiver. A hemodialysis patient is dependent on the machine, the procedure, and a team of trained healthcare professionals for the rest of his or her life. No other medical condition has such a high level of dependence on maintenance treatment for a chronic disease. Patients with kidney failure often have other medical conditions such as cardiovascular disorders, pulmonary diseases, neurological disorders, electrolyte disorders, etc. and require medications. All these factors play an important role in the emergence of various mental pathologies in these patients. An almost complete spectrum of mental disorders is observed. In a review study, common psychiatric disorders in dialysis patients were mood disorders, especially depression, organic brain diseases (e.g., dementia and delirium), drug-related disorders (e.g., alcoholism), schizophrenia and other psychotic disorders, personality disorders, etc. Various psychological factors in turn affect the long-term physical outcomes of patients. Various comorbid medical disorders may reduce compliance with complex prescribed diets and medications.

The number of people receiving hemodialysis increasing and increasing the number of health problems that have a negative effect. Therefore, Hemodialysis patients need treatment not only by health professionals, but also by caregivers.[1]

Family caregivers who shoulder more of the caregiving burden have lower quality of life. The researchers recommend that support and education programs be designed and implemented for this group of patients and caregivers.[2]

BACKGROUND:

Chronic renal failure is one of the chronic diseases, which, due to its persistent course, causes various effects on the physiological, psychological and functional abilities of the patient and his family.

Cantini conducted a descriptive study to investigate the burden of primary caregivers of dialysis patients. HD patients had a care burden of 13%, while the PD group had a higher burden of 35%. A cross-sectional study in Indonesia examined caregiving burden among 40 caregivers of family members receiving dialysis. The study assessed the potential relationship between caregiver burden and various factors, including gender and level of expertise. The results showed a statistically significant relationship between gender and knowledge level with a high care burden. However, no significant relationship was found between care burden and factors such as age, education level and duration of care. A recent 2020 study looked at a sample of 170 people who were family members of people with PD. The study found that 60% of these individuals experienced mild to moderate burden, while 18.2% reported moderate to severe burden. These findings were established using various assessment tools. [3]

There hasn't been much research on the quality of life (QoL) and mental health of people with chronic kidney disease (CKD), despite this being an increasing global concern.

The purpose of the study is to determine the prevalence of depression, anxiety, and quality of life (QoL) among hemodialysis patients with End Stage Renal Disease (ESRD) in Jordan and the correlation between these factors.[4]

NEED OF THE STUDY

There are no comparative studies on the quality of life of caregivers of hemodialysis patients in India and in Maharashtra in general. In addition, there is a lack of research on the clinical parameters of these patients and their relationship with quality of life. Quality is assessed using various standardized tools. Each tool is designed for a specific aimed. No single tool covers all parameters of the quality of life of hemodialysis patients and their caregivers.

When patients suffer from chronic illnesses (such as end-stage ESRD requiring dialysis), which are debilitating, costly, but temporary, the burden on caregivers increases exponentially, especially in a resource-poor country. Even in this context, studies that focus on the needs and burden of caregivers of hemodialysis patients are rare. It is important to understand the characteristics of caregivers and explore the relationship between their burden level, quality of life, and psychosocial aspects of the patients.

This will optimize the use of support measures, interventions, and help reduce the negative impact on the lives of caregivers. Since caregivers are mostly unpaid family members, the risk of burnout and depression can be frequent. Since studies on depressive symptoms among caregivers of patients undergoing hemodialysis are rare, the researcher attempted to assess the burden and depression among caregivers of HD patients.

PROBLEM STATEMENT

“A study to assess quality of life of caregiver of patients undergoing hemodialysis among selected hospitals.”

OBJECTIVES

1. To assess the quality of life of caregivers of patients undergoing hemodialysis.
2. To evaluate the factors affecting quality of life of caregivers of patients undergoing hemodialysis.
3. To find the association of quality of life of caregivers of patients undergoing hemodialysis with selected demographic variables.

HYPOTHESIS-

Ho- There is no significant difference between quality-of-life scores among caregivers of patients undergoing hemodialysis at different stages.

H1- There is a significant difference between quality-of-life scores among caregivers of patients undergoing haemodialysis at different stages.

VARIABLES-

Research Variable – Research variables in this study was the quality-of-life of caregivers of patients undergoing haemodialysis

METHODOLOGY:

RESEARCH APPROACH
The research approach adopted in this study was quantitative.

RESEARCH DESIGN
The research design used for this study was descriptive research.

SETTING OF THE STUDY
The setting for the current study was the hemodialysis unit of selected hospitals.

TARGET POPULATION
The target population for this study were caregivers of patients undergoing hemodialysis.

SAMPLE
In this study, the samples used were the caregivers of patients undergoing hemodialysis.

SAMPLE SIZE
The sample size for this study was 120.

SAMPLING TECHNIQUE
In this study, the simple random sampling technique was used.

SAMPLING CRITERIA
The sample was selected based on the following criteria.

INCLUSION CRITERIA
- Caregivers between the age group of 18 to 65 years.
- Caregivers who are willing to participate in the study.
- Caregivers who are first degree blood relatives of patients undergoing hemodialysis.

EXCLUSION CRITERIA
- Caregivers under 18 years old or over 65 years old.
- Caregivers are not willing to participate in this study.
- A caregiver who does not understand the Marathi, Hindi, English language.
- Caregivers with chronic conditions such as diabetes or hypertension that could significantly affect their own quality of life.

TOOLS AND TECHNIQUES OF DATA COLLECTION
In this study, consent was obtained from the study participants before data collection, then a structured questionnaire based on demographic variables and a caregiver burden scale were used as instruments, to evaluate the quality of life of caregivers of patients undergoing hemodialysis.

DESCRIPTION OF THE INSTRUMENT
The tools comprised of two parts.

PART-A: DEMOGRAPHIC VARIABLES
Demographic variables such as Age, Gender, Religion, Marital Status, Monthly Income, Educational status and Occupational Status.

PART-B: CAREGIVER BURDEN SCALE QUALITY OF LIFE
The caregiver burden scale was used to assess the quality of life of caregivers of patients undergoing hemodialysis. The caregiver burden scale included questions based on overall assessment of the quality of life of the caregiver, like caregiver comfort or discomfort while handling patients. Also included questions about dependency of the patient on the caregiver.

RELIABILITY
Reliability for the bio-physiological parameters was assessed using the test-retest method. Pearson's correlation coefficient was found to be 0.99.

PILOT STUDY
In this pilot study was conducted on 20 samples.

Section I

Description of samples (patients undergoing hemodialysis) based on their personal characteristics

Table 1: Description of samples (patients undergoing hemodialysis) based on their personal characteristics in terms of frequency and percentage

N=120

Demographic variable	Freq	%
Age of caregiver		
18 to 28 years	39	32.5%
29 to 40 years	53	44.2%
41 to 52 years	17	14.2%
53 to 65 years	11	9.2%
Gender		
Male	84	70.0%
Female	36	30.0%
Relationship with the patient		
Mother	7	5.8%
Father	10	8.3%
Brother	17	14.2%
Sister	8	6.7%
Husband	16	13.3%
Wife	10	8.3%
Son	36	30.0%
Daughter	10	8.3%
Other	6	5.0%
Type of family		
Nuclear	87	72.5%
Joint	25	20.8%
Extended	8	6.7%
Residence Area		
Urban	100	83.3%
Rural	20	16.7%
Marital status		
Married	61	50.8%
Single	48	40.0%
Divorced	4	3.3%
Widow	7	5.8%

Table 1 cont.

Demographic variable	Freq	%
Educational status		
No formal education	7	5.8%
Primary	19	15.8%
Secondary	45	37.5%
Higher secondary	37	30.8%
Graduation	9	7.5%
Post-graduation	3	2.5%
Occupational Income		
Unemployed	47	39.2%
Self-employed	43	35.8%
In service	21	17.5%
Retired	4	3.3%
Other	5	4.2%
Religion		
Hindu	80	66.7%
Muslim	2	1.7%
Buddhist	28	23.3%
Other	10	8.3%
Monthly income		
Up to Rs.10,000	6	5.0%
Rs.10,001 – Rs.20,000	39	32.5%
Rs. 20,001- Rs. 30,000	58	48.3%
Above Rs. 30,000	17	14.2%

Table 1 shows that, 44.2% of them had age 29 to 40 years, 70% of them were males and 30% of them were females, 30% of them were son, 72.5% of them had nuclear family, 83.3% of them were from urban area, 50.8% of them were married, 37.5% of them had secondary education, 39.2% of them were unemployed, 66.7% of them were Hindu, 48.3% of them had monthly income Rs. 20001-30000.

Section II

Analysis of data related to quality of life of caregivers of patients undergoing hemodialysis

Table 2: Quality of life of caregivers of patients undergoing hemodialysis

N=120

Quality of life	Freq	%
Little or no burden	44	36.7%
Mild burden	36	30.0%
Moderate burden	35	29.2%
Severe burden	5	4.2%

Table 2 reveals that, 36.7% (44) of the caregivers of patients undergoing hemodialysis had little or no burden, 30% (36) of them had mild burden, 29.2% (35) of them had moderate burden and 4.2% (5) of them had severe burden.

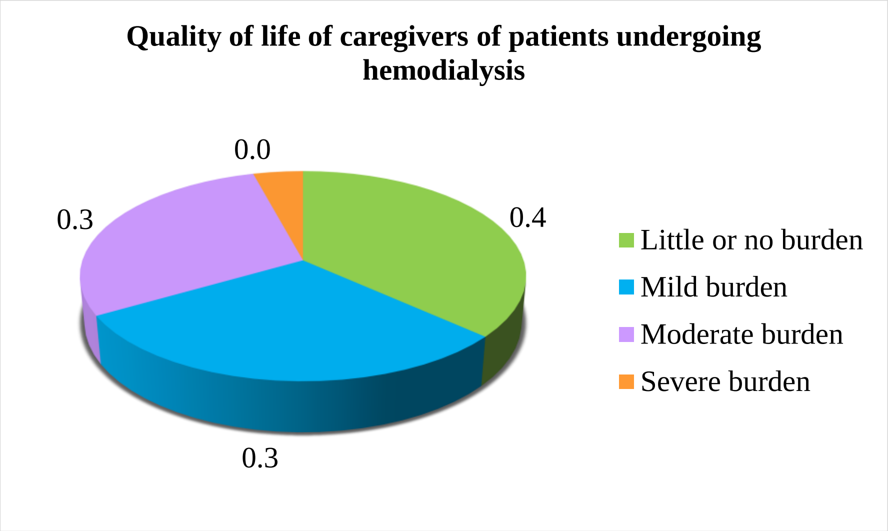

Table 3: Item analysis

N=120

QOL Item		Freq	%
Do you feel that your relative asks for more help than he or she needs	Never	56	46.7%
	Rarely	30	25.0%
	Sometimes	28	23.3%
	Frequently	6	5.0%
Do you feel that because of the time you spend with your relative, you do not have enough time for yourself	Never	41	34.2%
	Rarely	28	23.3%
	Sometimes	42	35.0%
	Frequently	9	7.5%
Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work	Never	17	14.2%
	Rarely	26	21.7%
	Sometimes	30	25.0%
	Frequently	35	29.2%
	Nearly always	12	10.0%
Do you feel embarrassed over your relative's behaviour	Never	86	71.7%
	Rarely	24	20.0%
	Sometimes	9	7.5%
	Frequently	1	0.8%
Do you feel angry when you are around your relative	Never	72	60.0%
	Rarely	32	26.7%
	Sometimes	14	11.7%
	Frequently	2	1.7%
	Never	45	37.5%

Do you feel that your relative Currently affects your relationship with other family members or friends in a negative way	Rarely	33	27.5%
	Sometimes	38	31.7%
	Frequently	4	3.3%
Are you afraid about what the future holds for your relative	Never	4	3.3%
	Rarely	27	22.5%
	Sometimes	36	30.0%
	Frequently	24	20.0%
	Nearly always	29	24.2%
Do you feel your relative is dependent on you	Never	42	35.0%
	Rarely	28	23.3%
	Sometimes	37	30.8%
	Frequently	10	8.3%
	Nearly always	3	2.5%

Table 3 cont.

QOL item		Freq	%
Do you feel strained when you are around your relative	Never	18	15.0%
	Rarely	29	24.2%
	Sometimes	29	24.2%
	Frequently	30	25.0%
	Nearly always	14	11.7%
Do you feel your health has suffered because of your involvement with your relative	Never	52	43.3%
	Rarely	35	29.2%
	Sometimes	29	24.2%
	Frequently	3	2.5%
	Nearly always	1	0.8%
Do you feel that you do not have as much Privacy as you would like, because of your relative	Never	50	41.7%
	Rarely	26	21.7%
	Sometimes	38	31.7%
	Frequently	5	4.2%
	Nearly always	1	0.8%
Do you feel that your social life has suffered Because you are caring for your relative	Never	32	26.7%
	Rarely	33	27.5%
	Sometimes	32	26.7%
	Frequently	20	16.7%
	Nearly always	3	2.5%
Do you feel uncomfortable about having friends over, because of your relative	Never	74	61.7%
	Rarely	32	26.7%
	Sometimes	11	9.2%
	Frequently	3	2.5%
Do you feel that your relative seems to expect you to take care of him or her, as if you were the only one, he or she could depend on	Never	44	36.7%
	Rarely	24	20.0%
	Sometimes	34	28.3%
	Frequently	18	15.0%
Do you feel that you do not have enough money to care for your relative, in addition to the rest of your expenses	Never	26	21.7%
	Rarely	18	15.0%
	Sometimes	31	25.8%
	Frequently	33	27.5%
	Nearly always	12	10.0%
Do you feel that you will be unable to take care of your relative much longer	Never	56	46.7%
	Rarely	30	25.0%
	Sometimes	26	21.7%
	Frequently	7	5.8%
	Nearly always	1	0.8%

Table 3 cont.

QOL item		Freq	%
Do you feel you have lost control of your life since your relative's illness	Never	46	38.3%
	Rarely	27	22.5%
	Sometimes	39	32.5%
	Frequently	7	5.8%
	Nearly always	1	0.8%
Do you wish you could just leave the care of your relative to someone else	Never	63	52.5%
	Rarely	21	17.5%
	Sometimes	26	21.7%
	Frequently	8	6.7%
	Nearly always	2	1.7%
Do you feel uncertain about what to do about your relative	Never	35	29.2%
	Rarely	22	18.3%
	Sometimes	34	28.3%
	Frequently	21	17.5%
	Nearly always	8	6.7%
Do you feel you should be doing more for your relative	Never	3	2.5%
	Rarely	32	26.7%
	Sometimes	41	34.2%
	Frequently	23	19.2%
	Nearly always	21	17.5%
Do you feel you could do a better job in caring for your relative	Never	4	3.3%
	Rarely	38	31.7%
	Sometimes	53	44.2%
	Frequently	15	12.5%
	Nearly always	10	8.3%
Overall, how burdened do you feel in caring for your relative	Rarely	35	29.2%
	Sometimes	23	19.2%
	Frequently	28	23.3%
	Nearly always	34	28.3%

Table 3 shows that, 46.7% of the caregivers of patients undergoing hemodialysis never, feel that their relative asks for more help than he or she needs. 35% of them sometimes feel that because of the time they spend with their relative, they do not have enough time for themselves. 29.2% of them frequently feel stressed between caring for their relative and trying to meet other responsibilities for their family or work. 71.7% of them never feel embarrassed over their relative's behavior. 60% of them never feel angry when they are around their relative.

37.5% of them never feel that their relative Currently affects their relationship with other family members or friends in a negative way. 30% of them sometimes afraid about what the future holds for their relative. 35% of them never feel their relative is dependent on them. 25% of them frequently feel strained when they are around their relative. 43.3% of them never feel their health has suffered because of their involvement with their relative. 41.7% of them never feel that they do not have as much Privacy as they would like, because of their relative.

27.5% of them rarely feel that their social life has suffered Because they are caring for their relative. 61.7% of them never feel uncomfortable about having friends over, because of their relative. 36.7% of them never feel that their relative seems to expect them to take care of him or her, as if they were the only one, he or she could depend on. 27.5% of them frequently feel that they do not have enough money to care for their relative, in addition to the rest of their expenses. 46.7% of them never feel that they will be unable to take care of their relative much longer. 38.3% of them never feel they have lost control of their life since their relative's illness.

52.5% of them never wish they could just leave the care of their relative to someone else. 29.2% of them never feel uncertain about what to do about their relative. 44.2% of them sometimes feel burdened in caring for their relative.

Section III

Analysis of data related to the association of quality of life of caregivers of patients undergoing hemodialysis with selected demographic variables

Table 4: Fisher's exact test for the association of quality of life of caregivers of patients undergoing hemodialysis with selected demographic variables

N=120

Demographic variable		**Quality of life**				
		Little or no burden	**Mild burden**	**Moderate burden**	**Severe burden**	**p-value**
Age of caregiver	18 to 28 years	15	13	11	0	0.540
	29 to 40 years	17	18	15	3	
	41 to 52 years	6	3	7	1	
	53 to 65 years	6	2	2	1	
Gender	Male	27	29	23	5	0.128
	Female	17	7	12	0	
Relationship with the patient	Mother	5	0	2	0	0.199
	Father	4	3	2	1	
	Brother	8	2	6	1	
	Sister	3	1	4	0	
	Husband	5	5	5	1	
	Wife	4	3	3	0	
	Son	10	18	7	1	
	Daughter	5	3	2	0	
	Other	0	1	4	1	
Type of family	Nuclear	31	26	25	5	0.834
	Joint	9	7	9	0	
	Extended	4	3	1	0	
Residence Area	Urban	35	31	29	5	0.776
	Rural	9	5	6	0	
Marital status	Married	18	20	19	4	0.180
	Single	21	16	10	1	
	Divorced	1	0	3	0	
	Widow	4	0	3	0	
Educational status	No formal education	4	2	1	0	0.275
	Primary	9	3	6	1	
	Secondary	10	19	13	3	
	Higher secondary	15	11	10	1	
	Graduation	3	1	5	0	
	Post-graduation	3	0	0	0	

Table 4 cont.

Demographic variable		**Quality of life**				
		Little or no burden	**Mild burden**	**Moderate burden**	**Severe burden**	**p-value**
Occupational Income	Unemployed	22	14	11	0	0.258
	Self-employed	10	13	15	5	
	In service	8	7	6	0	
	Retired	1	1	2	0	
	Other	3	1	1	0	
Religion	Hindu	33	22	22	3	0.666
	Muslim	0	1	1	0	
	Buddhist	7	10	10	1	
	Other	4	3	2	1	
Monthly income	Up to Rs.10,000	4	1	1	0	0.766
	Rs.10,001 – Rs.20,000	13	14	10	2	
	Rs. 20,001- Rs. 30,000	22	14	20	2	
	Above Rs. 30,000	5	7	4	1	

Table 4 shows that, all the p-values were large (greater than 0.05), hence none of the demographic variables were found to have significant association with the quality of life among caregivers of patients undergoing hemodialysis.

DISCUSSION

A study was conducted on “Effectiveness of Problem-Focused Coping Strategies on the Burden on Caregivers of Hemodialysis Patients” in Shahid Hasheminejad hemodialysis centre in Tehran, Iran, on 21 May 2016 with aimed to explore the impact of problem-focused coping strategies (communication skills, anger management, and deep breathing) on the burden experienced by caregivers of hemodialysis patients. Studies have shown that family caregivers of hemodialysis patients experience considerable levels of burden. The participants were randomly assigned into two groups of 38 individuals each. Using a coin-flipping method, caregivers of patients referred on even or odd days were allocated to either the intervention group or the control group. The intervention group took part in four training sessions centred around problem-focused coping strategies, whereas the control group received no intervention. Both groups filled out the caregiver's burnout inventory at the start and six weeks after the final educational session. Data analysis was done using descriptive statistics, chi-square, Fisher's exact test, independent-samples t-test, and Mann-Whitney U test. The majority of caregivers (54%) were aged between 35-55 years, were primarily female (68.4%), and were married (70%). There was no significant difference found between the baseline mean caregiver burden scores of the intervention and control groups (88. 56 ± 11. 74 vs. 84. 97 ± 15. 13, P = 0. 308). However, the mean caregiver burden in the intervention group showed a reduction, and the two groups exhibited significant differences at the end of the study (58. 77 ± 6. 64 vs. 87. 84 ± 11. 74, P<0.001).[5]

Similarly, in this study, 120 caregivers of patients undergoing hemodialysis were selected as study samples by random sampling technique. FTLDA-Caregiver Burden Scale was administered to assess the Quality of Life of caregivers of patients undergoing hemodialysis. In this study, there are 22 questions and each question assessed the quality of life of caregivers of patients undergoing hemodialysis. (Score range 0-4; Never:0, Rarely:1, Sometimes:2, Frequently:3, Nearly Always:4, higher values indicate greater impact.)

Data regarding demography was collected using a demographic questionnaire. Data analysis was done using descriptive statistics, Fisher's exact test was used to find out the association of demographic variables with the quality of life of caregivers of patients undergoing hemodialysis. Data analysis revealed that all the p-values were large (greater than 0.05), therefore none of the demographic variables were found to have a significant association with the quality of life among caregivers of patients undergoing hemodialysis.

CONCLUSION

The conclusion drawn from the findings of the study is that, caregivers of hemodialysis patients often experience reduced quality of life due to significant responsibilities, influenced by dialysis type and medication costs. Family support can alleviate burdens, while socio-economic assistance enhances their situations. Additionally, caregivers provide valuable insights to professionals, addressing shared psychological and physical challenges.

LIMITATIONS

- The study was limited to the caregivers between the age group 18 to 65 years.
- The duration of the study was 1 month.
- The study is limited in sample size of 120.

REFERENCES

1. Grapsa Eirini and Gerogianni Georgia, “Caregivers of Patients on Haemodialysis”, DOI: 10.5772/intechopen.72400
2. Sedigheh Farzi, PhD Saba Farzi, PhD Candidate Azam Moladoost, PhD Candidate Maryam Ehsani, PhD Mohsen Shahriari, PhD Mahin Moieni, MS “Caring Burden and Quality of Life of Family Caregivers in Patients Undergoing Hemodialysis: A Descriptive-Analytic Study”, Doi: 10.30476/IJCBNM.2019.44888
3. Abdullah A. Alaryni, Fadel Alrowaie, Abdullah Alghamdi, Razan Alabdullah, et.al. “Assessment of Burden in Caregivers of Patients Undergoing Hemodialysis and Peritoneal Dialysis: A Cross-Sectional Study” in Riyadh, Saudi Arabia, DOI: 10.7759/cureus.52513
4. Sameeha Alshell, Hussein Alhawari, Abdullah Alhour, Bilal Abu-Hussein, Ashraf Oweis, “Level of Depression and Anxiety on Quality of Life Among Patients Undergoing Hemodialysis”, Doi: 10.2147/IJGM.S406535.
5. Ghane, G., Farahani, M. A., Seyedfatemi, N., & Haghani, H. (2016). Effectiveness of Problem-Focused coping strategies on the burden on caregivers of hemodialysis patients. Nursing and Midwifery Studies, 5(2). https://doi.org/10.17795/nmsjournal35594