Family Caregivers' Burden of Hemodialysis Elderly Patients at Assiut City

Asmaa B Hassan[1], Hoda D. F. Ibrahim[2], Soad A. El H Sharkawy[3], Hanan A. Abo-Zaid[4]
1. Nursing Specialist at Technical Nursing Institute, Assiut University, Egypt.
2. Professor of Community Health Nursing, Faculty of Nursing, Assiut University, Egypt.
3. Assistant Professor of Community Health Nursing, Faculty of Nursing, Assiut University, Egypt.
4. Lecturer of Gerontological Nursing, Faculty of Nursing, Assiut University, Egypt.

Abstract
Background: One in 10 elderly people worldwide have kidney disease, according to the first detailed global report on care delivery for kidney disease, family caregivers of hemodialysis patients experience high levels of burden. **Aim of the study to** assess family caregivers' burden of hemodialysis elderly patients **Subjects and method:** This study included 83 family caregivers were participated in the study. Descriptive research design carried out in the present study for hemodialysis patients' family caregivers within all hemodialysis units at Assiut city. Convenient sample are used in this study by total coverage technique. An interview questionnaire designed by the researchers after reviewed the related literature; it was structured into three parts: Part (1): Care givers personal data and properties, Part (2): Caregivers knowledge about CKD, Part (3):Zarit Sh Caregiver Burden Scale that used to assess caregivers' burden.. **Results:** Only 1.2% of caregivers had mild burden& 71.1%had severe burden. **Conclusion:** it is concluded that there was a high percent of studied caregivers had severe burden, also 38.6% of them had good knowledge. **Recommendations:** Involving family caregivers counseling and coping mechanisms regarding hemodialysis elderly patients to decrease burden's level.

Key words: Hemodialysis, Elderly, Family Caregivers & Burden.

Introduction
The world's elderly population is expected to be 2 billion in the year 2020, most of which will be living in developing countries that can least afford the health care burden encountered by this population group. In Egypt, The Central Agency of Public Mobilization and Statistics (CAPMUS) has reported that elder people in 2016 was around 8.9%, while the expected percentage will be 10.9% in 2026. The life expectancy for male elders expected to be 19.3 years in 2026 **(CAPMUS, 2016).**

The elderly population is the most rapidly growing population segment in the western world. It is estimated that by 2025, there will be over 800 million individuals over the age of 65 worldwide **(Xinhui, et al., 2014).**

Chronic kidney disease (CKD) is a global health burden with a high economic cost to health systems and is an independent risk factor for cardiovascular disease (CVD). All stages of CKD are associated with increased risks of cardiovascular morbidity, premature mortality, and/or decreased quality of life. CKD is usually asymptomatic until later stages and accurate prevalence data are lacking. To determine the prevalence of CKD globally, by stage, geographical location, gender and age **(Nathan, et al., 2016).**

End stage renal disease affects almost all aspects of life of the patients and their caregivers. The caregiver role is stressful and demanding but is often neglected, especially in developing countries. Family caregivers of hemodialysis patients experience high levels of burden. However, these caregivers are often neglected, and no studies are available on the effectiveness of coping strategies on the burden of care among these caregivers **(Golnar, et al., 2016).**

The significance of the Study
Studies suggest that family caregivers of hemodialysis patients experience a high level of burden, which could lead to numerous physical and psychological problems. Despite the need for adequate training and support, caregivers are mostly neglected, and few studies have been performed in this regard. Caregivers of hemodialysis patients are facing significant burden and more than one third are moderate to severely depressed. Interventions to provide appropriate social support services and improve psychological conditions of caregivers are of urgent and paramount importance **(Mansoureh, et al., 2016).**

Research Questions
- Do the family caregivers of the hemodialysis elderly patients have caregiving burden?
- Do the family caregivers of hemodialysis elderly patients have lack of knowledge in according to CKD?

The aim of the study: To assess the family caregivers' burden of hemodialysis elderly patients in Assiut city.

Subjects & Method
Research design: Descriptive research design was carried out for this study.

Setting: The study carried out in all hemodialysis units at Assiut city; it is includes: Assiut University Hospital's hemodialysis unit**,** Health Insurance Hospital's hemodialysis unit**,** Al- Iman General Hospital's hemodialysis unit, Assiut General Hospital's hemodialysis unit, and Assiut Fever Hospital's hemodialysis unit**.**

Subjects: The target population of the study are **included all** family caregivers that attends the hemodialysis unit with their elderly patients in the previous mentioned setting who accept to participate in the study, Which included **83** family caregivers (23 males and 60 females).

Sample and Sampling: Convenient sample are used in this study. The patients' family caregivers are selected by total coverage technique, according to their participation in the study and had inclusion criteria.

Tool of the study

An interview form for care givers**,** it was designed by the researcher after reviewed the related literature; it was **structured into three parts**

Part (1): family Caregivers personal data and properties that included occupation, education, residence, etc.., and their relationship to care recipient that discuss duration of caregiving, household status, financial status, employment status, and transportation.

Part (2): Caregivers knowledge sheet that included closed ended questions about renal functions & causes, risk factors, symptoms of end stage renal failure, hemodialysis, nutrition of patients, burden's types, sources of burden, and management of burden

scoring system for knowledge

- The score of each item summed-up and then converted into percent score (poor= score<50%, satisfactory=score 50-70%, and good= score>70 percentage**) (Parvan et al., 2012).**
- **Part (3): Zarit Sh Caregiver Burden Scale,** 22-item questionnaire to assess the experience of burden, Likert Scale statement ranged from (0= never, 5= almost always). The necessary modification in the scale was done to be suitable to the study conditions as following:
- Likert Scale statement ranged from (1= never, 3= almost always), **it's scoring system as following:** it's summed-up and then converted into percent score as following <50% indicates little or no burden score between 50-69% indicates mild to moderate burden, and 70 % and more indicates severe burden (**Zarit, et al., 2002**).

Validity: The tool was reviewed by 5 experts in the field of nursing science who reviewed the instrument for clarity, relevance, understanding, and applicability.

Reliability: The Cornbrash's alpha coefficient for the instrument was 0.94 with a test-retest reliability of 0.94.

Methodology:

I- Administrative phase

An official letter approval was obtained from the Dean of the Faculty of Nursing Assiut University to the previous mentioned settings and an official letter approval was obtained from each mentioned setting which includes a permission to carry out the study in the selected hemodialysis units.

II- Ethical considerations

The research proposal was approved from ethical committee in the faculty of nursing, there is no risk for the study' subjects during the carrying out of the research, participants were advised of their rights to withdraw from the study at any time, participants were coded for data entry so their names couldn't be identified, participant agreement for voluntary participation was obtained and the nature of the study was explained, while confidentiality anonymity was assured.

Pilot study

Pilot study was carried out before starting data collection on 10 percent from the elderly and their caregivers. It aimed to test the clarity of the tools and to estimate the required time to fill the questionnaire, and the pilot study was included in the study.

Field work

The researcher started to collect data from started at the first of September to the end of November, 2017. After obtaining approval for conducting the research study, the researchers referred to the dialysis unit in every previous mentioned hospital setting and all the patients' family caregivers were selected. Afterwards, the researcher contacted the caregivers to assess their eligibility and give details about the aim of the study. The interview occurred at hemodialysis unit or in the hall area according to hospital facilities in every previous mentioned setting in Asyut city. Each interview took about (30-40) minutes to fill the questionnaire. Every day from 1 to 4 interviews of forms finished, interviews done at morning, and afternoon shifts.

V. Statistical analysis and scoring system

The obtained data reviewed, prepared for computer entry, coded, analyzed, and tabulated. Categorical variables were described by number and percent. All analyses were performed with the IBM SPSS 20.0 software version.

Results

Table (1): socio demographic characteristics distribution of studied family care givers of hemodialysis elderly patients, Assuit city' hospitals, 2017 (No. 83).

Items of Personal characteristics	No= 83	%
Age		
18 - < 35 years	50	64.0
35 - < 50 years	20	24.0
50 and more	10	12.0
Range (18 years -69 years)	Mean± SD 41.37±12.76	
Gender Male	23	27.7
Female	60	72.3
Marital Status Single	20	24.1
Married	59	71.1
Divorced	2	2.4
Widowed	2	2.4
Level of Education Illiterate	3	3.6
Write and read	9	10.8
Basic education	50	60.2
Secondary education	3	3.6
University	18	21.7
Occupation Housewife	29	35.0
Free work	29	35.0
Employee	25	30.0
Residence Rural	38	45.8
Urban	45	54.2

Table (2): The degree of consanguinity of studies family care givers with the studied hemodialysis elderly, at Assuit city' hospitals, 2017 (No. 83).

Degree of consanguinity	No= 83	%
Husband /Wife	28	33.7
Son / Daughter	36	43.4
Brother/ sister	2	2.4
Other family members	17	22.5
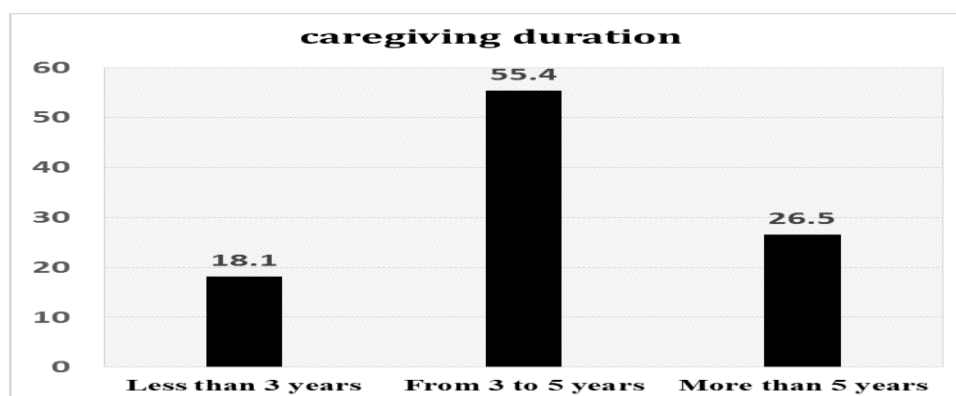
Figure (1): Distribution of studied caregivers regarding caregiving duration of their elderly patients.

Table (3): total score of knowledge among studied family caregivers about Chronic Kidney Disease of hemodialysis elderly patients, at Assuit city hospital, 2017 (No= 83) .

Score of knowledge (Knowledge level)	No= 83	%
Poor ≤ 50%	25	30.1
Good 51%-70%	32	38.6
Very good to Excellent ≥ 71%	26	31.3

Table (4): caregivers' knowledge about caregivers'adaptation methods with burden of hemodialysis elderly patients, at Assuit city' hospitals, 2017 (No=83).

Item of knowledge		
Negative Burden' adaptation methods # 1) Smoking	No 20	% 24.1
2) Over eating	17	20.5
3) Waste time in front of the TV or computer	51	61.4
4) Withdrawal from friends, family, activities	24	28.9
5) Use medicines to relax	22	26.5
6) Sleep too much	31	37.3
7) procrastination	56	67.5
8) projection (by violent attackand physical violence)	41	49.4

 # More than one answer

Positive burden' adaptation methods #

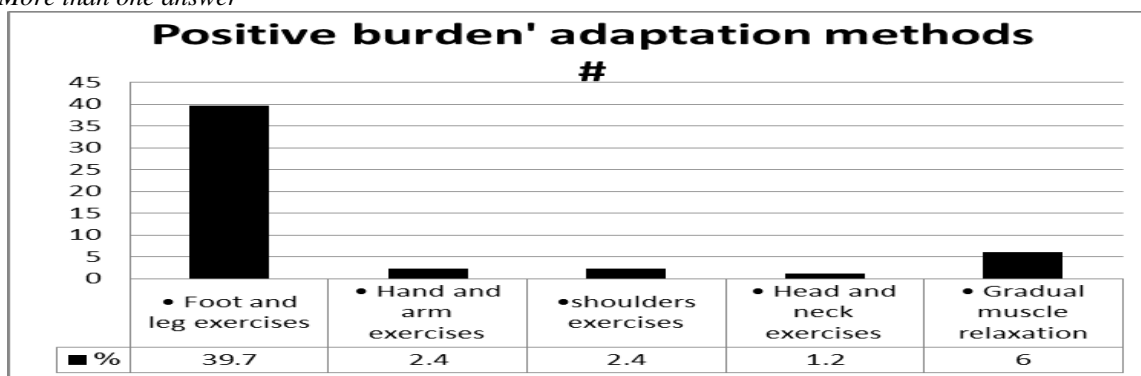|	Foot and leg exercises	Hand and arm exercises	shoulders exercises	Head and neck exercises	Gradual muscle relaxation
%	39.7	2.4	2.4	1.2	6

Figure (2): distribution of positive methods that caregivers used to cope with burden at Assuit city, 2017

Table (5): Distribution of studied family caregivers as regard to total care giver burden, at Assuit city' hospitals, 2017 (No. = 83).

Caregivers' burden	No	%
Little or no burden	1	1.2
Mild to Moderate	23	27.7
Severe	59	71.1

Table (6): Relationship between total caregivers' burden and socio-demographic characteristics of the studied family caregivers of hemodialysis elderly patients, at Assuit' Hospitals, 2017(No= 83).

Socio-demographic characteristics	Caregivers burden scale						p- value
	Little or no burden		Mild / Moderate		Severe		
	No	%	No	%	No	%	
Gender Male	1	1.2	9	10.8	13	15.7	
Female	0	0.0	14	16.9	46	55.4	0.080
Marital Status Single	0	0.0	7	8.4	13	15.7	
Married	1	1.2	15	18.0	43	51.8	0.890
Divorced	0	0.0	1	1.2	1	1.2	
Widowed	0	0.0	0	0.0	2	2.4	
Education level Illiterate	0	0.0	0	0.0	3	3.6	
Write and read	0	0.0	3	3.6	6	7.2	
Basic education	0	0.0	11	13.2	39	47.0	0.847
Sec. education	0	0.0	3	3.6	0	0.0	
University	1	1.2	6	7.2	11	13.2	
Occupation Housewife	0	0.0	1	1.2	28	33.7	
Free work	0	0.0	11	13.2	18	21.6	0.639
Employee	1	1.2	11	13.2	13	15.7	
Residence Rural	1	1.2	11	13.2	26	31.3	
Urban	0	0.0	12	14.5	33	39.7	0.524

*Chi-square test, *statistically significance difference (p<0.05)*

Table (1): Shows the sociodemographic data characteristics of the studied family care givers were found that, the average age of them was ranged from 18 to 69 and more years old, while Mean± SD of age was 41.37±12.76, in which 35.0% of them were house wife and 72.3%, 71.1% were females and married respectively.

Table (2): Show consanguinity degree of the studied family care givers with the elderly, in which 43.4& 33.7 of the studied caregivers were sons /daughter& Husband / Wife of the studied elderly respectively.

Figure (1): Illustrate that 55.4% of the studied family caregivers had caregiving since 3-5 years ago toward their studied elderly, in which 26.5 of them had caregiving since 5 years ago.

Table (3): Illustrate the knowledge of studied family caregivers regarding to roles of caregivers, in which 84.3%, 74.7% provide medication /physiotherapy &Provide psychological support to adapt to the disease.

Table (4): Shows negative adaptation methods that 61.4%, 67.5% of caregivers used to waste time in front of TV and computer and use procrastination as negative adaptation methods, respectively.

Regarded to positive adaptation methods, **figure (2)** illustrate that 39.7% &6.0% of caregivers used foot /leg exercise & gradual muscle relaxation, respectively.

Table (5): Shows that only 1.2% of caregivers had mild to moderate burden& 71.1%had severe burden.

Table (6): Shows that 55.4%, 51.8% &39.7% of the studied caregivers were females, married, and from the urban area had a severe burden. There was no statistically significant difference in according to socio-demographic characteristics and the burden of studied family caregivers.

Discussion

According to the literature, family caregivers play a pivotal role in the care of patients and are under tremendous physical and psychological pressure. In east culture, it is supposed that women, by their very nature, should give birth, do housework, serve the husband, and grandparents **(Bahar, et al., 2013)** the finding of the present study revealed that the age average of the studied family care givers was ranged from 18 to 69 while Mean± SD of age was 41.37±12.76, and more years old, in which one third

of them were house wife and less than three quarter were females and married.

The current results was agreed with (**Adel & Abdul Manaf, 2012**) who conduct a study about Quality of Life of Caregivers and Patients Undergoing Haemodialysis at Ministry of Health, Jordan, in which the majority of the studied caregivers had the same characteristics that mentioned.

In addition, the present study presented that less than half of the studied family caregivers were son or daughter, according to American Sociological Association (ASA). "Daughters provide as much elderly parent care as they can), the current study was in the same line with (**Adel & Abdul Manaf, 2012**) found that more than half of the studied family caregivers were son or daughter.

In the present study the researcher was investigated the burden of the caregivers of hemodialysis patients and reported that about three quarter of these family care givers experienced severe burden, this results in the line with (**Farahani, et al., 2016**) who conducted a study about Effect of Educational Program on the Burden of Family Caregivers of Hemodialysis Patients.

According to total caregivers burden the finding in the present study clear that little more than one quarter of the studied caregivers showed mild to moderate burden, While **Mansoureh, et al., (2016)** who conducted a study in Iran about Effect of Educational Program on the Burden of Family Caregivers of Hemodialysis Patients who reported that about one tenth of the studied caregivers experienced mild to moderate burden and the majority of them experience sever burden

The findings of this study give insight into the difficulties of providing adequate care for patients with a chronic disease such as End Stage Renal Disease. The aspects that arose from current data analysis indicated that there was a considerable amount of psychosocial and physical burden that had an impact on various aspects of caregiver's well-being, in which the majority of the studied caregivers had psychological & physical burden

In the same line with current study a study that conducted by (**Alnazly & Samara, 2014**) about The Burden On Caregivers Of Patients Above 65 Years Old Receiving Hemodialysis: A Qualitative Study, Amman, Jordan who reported that the majority of the studied caregivers had psychological & physical burden. This was agreed with (**Hassan, 2017**) who reported that the majority of the studied caregivers had psychological, financial, and physical burden.

Conclusion & Recommendation
Based on the results of the present study, it can be concluded that
In consider of burden level of caregivers, more than two third of the studied caregivers had sever burden, and more than half of females and married caregivers had sever burden.

Recommendation
Involving family caregivers counseling and coping mechanisms regarding care for hemodialysis elderly patients to decrease burden's level.

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