

HOSTED BY



Contents lists available at ScienceDirect

International Journal of Nursing Sciences

journal homepage: <http://www.elsevier.com/journals/international-journal-of-nursing-sciences/2352-0132>



Special Issue: Advanced Practice Nursing

The impact of an educational intervention in caregiving outcomes in Jordanian caregivers of patients receiving hemodialysis: A single group pre-and-post test



Eman Khamis Alnazly

Nursing Department, Al-Ahliyya Amman University, Jordan

ARTICLE INFO

Article history:

Received 6 November 2017

Received in revised form

20 March 2018

Accepted 23 March 2018

Available online 30 March 2018

Keywords:

Burden

Caregiver

Hemodialysis

Informative materials

Self-perceived burden

ABSTRACT

Objectives: Chronic renal failure affects the physiological, psychological, functional ability, and independent status of the patient, which might result in a burden to the family members caring for them. The objective of the study was to identify caregivers' level of burden and establish the impact of educational intervention programs on caregiving outcomes.

Methods: This was a one-group pre-test post-test study conducted between April and August 2017 on family caregivers of hemodialysis patients. A convenient sample of 169 caregivers was used. A socio-demographic questionnaire, the OBCS, and BCOS were utilized for data collection, which occurred at baseline and two weeks post-intervention. The collected data were analyzed using SPSS where *t*-test determined the impact of the intervention.

Results: Caregivers were found to be moderately burdened ($M = 2.73$, $SD = 0.23$) and their lives had changed for the worst as a result of caregiving ($M = 3.17$, $SD = 5.89$). There were significant differences in caregiving outcome scores before and after the intervention ($P < 0.05$).

Conclusion: Caring for patients receiving hemodialysis adds extra responsibilities to the caregivers' schedule thus leaving them substantially burdened. Educating caregivers on the required care eased their burden and improved caregiving outcomes. Recommendations are made that healthcare professionals should assess caregiver burden, and address their physical and mental health needs. Caregivers should also be regularly educated on the regular caregiving tasks to ease their burden.

© 2018 Chinese Nursing Association. Production and hosting by Elsevier B.V. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

1. Introduction

Family caregivers provide free physical and emotional related assistance to relatives or close friends with physical illness, mental illness, or other conditions [1]. Family caregiving has been associated with physical, mental, and financial burden to caregivers [2,3]. Current literature reveals that family caregivers of patients receiving hemodialysis frequently report burden and poor mental health [4,5]. Family caregivers face significant challenges including emotional distress, deterioration of physical health, and impaired quality of life [5,6]. Advanced Practice Nurses (APNs) need to understand the burden of chronic patient caregivers to improve health outcomes for both patients and caregivers [6].

A study on family caregivers' burden revealed that caregivers

had concerns about caregiving tasks and maintaining their own physical and mental well-being [7]. Creedle et al. [8] reported that a standardized educational program addressing the physical and emotional needs of both patients and caregivers resulted in positive outcomes. Martín-Carrasco et al. [9] found an educational program comprising of teaching strategies for confronting problems, caregiver's stress, and quality of life as effective in easing burden, improving well-being perception, and a lowering risk of developing psychiatric disorders in caregivers of patients with Alzheimer's disease. Supporting caregivers helps meet their unfulfilled needs and addresses care recipients' personal care and medical needs [1]. Similarly, optimal caregiver support maintains caregiver's physical and mental health. With the increase of care recipients' needs and dependence on the caregiver, their ability to keep up with caregiving tasks is negatively affected. A caregiver intervention based on caregivers' needs may improve both the caregivers' and care recipients' well-being. Evidence-based practice interventions have been developed to minimize caregiving burden, enhance

E-mail address: emanalnazly@hotmail.com.

Peer review under responsibility of Chinese Nursing Association.

caregivers' well-being, and optimize patient outcomes [1].

Efforts to support family caregivers are focused on services such as educational programs, caregiver counseling, respite care, and caregiver support groups [6]. The caregivers' information and educational intervention approach is likely to reduce their burden and improve the patients' health [6]. In a recent study on caregivers' needs, the findings indicated that family caregivers lack sufficient information regarding the disease progression, patient home care, hemodialysis nutritional diet, and medication therapy [10]. One of APNs' core practices is to educate caregivers of chronic patients on the progression of the diseases and home care to ease their burden and improve health outcomes for the patient [6].

This research study aimed at identifying caregiver burden and establishing the impact of an educational intervention program on hemodialysis on caregiving outcomes. The objective of the interventional program was to promote positive caregiving outcomes. The Outcome-Based Learning (OBL), introduced by William Spady, was adopted for this study. The OBL model focuses on organizing educational programs where students achieve the outcomes by the end of the program [11]. According to Spady, students will do exceptionally well if the education systems are focused an organized around their needs [11]. Assuming that family caregivers experience negative outcomes as a result of providing home care, the intervention will be focused on hemodialysis patient care needs and easing caregiving, to improve the overall well-being of the caregivers (Fig. 1).

2. Methods

2.1. Research design

One-group pre-test post-test design was used to conduct this study. One-group pre-test post-test design is part of quasi-experimental research designs, which utilizes a single group of research participants. Data were collected before and after the intervention. A significant difference in the pre-test and post-test scores was an indicator that the intervention program improved caregivers' outcomes.

2.2. Sample size

To determine a convenient sample size, a power analysis was conducted using 0.05 as the level of significance, 0.95 as the power, and effect size of 0.25. The minimum required sample size obtained was 164 caregivers. A total of 169 participants agreed to participate in the study.

2.3. Participants selection

A convenience sampling technique was used to recruit family caregivers that met the inclusion criteria. Two nurses from each dialysis unit recruited family caregivers of hemodialysis patients who frequented the clinic and met the inclusion criteria. The inclusion criteria for caregivers included being unpaid, identified by

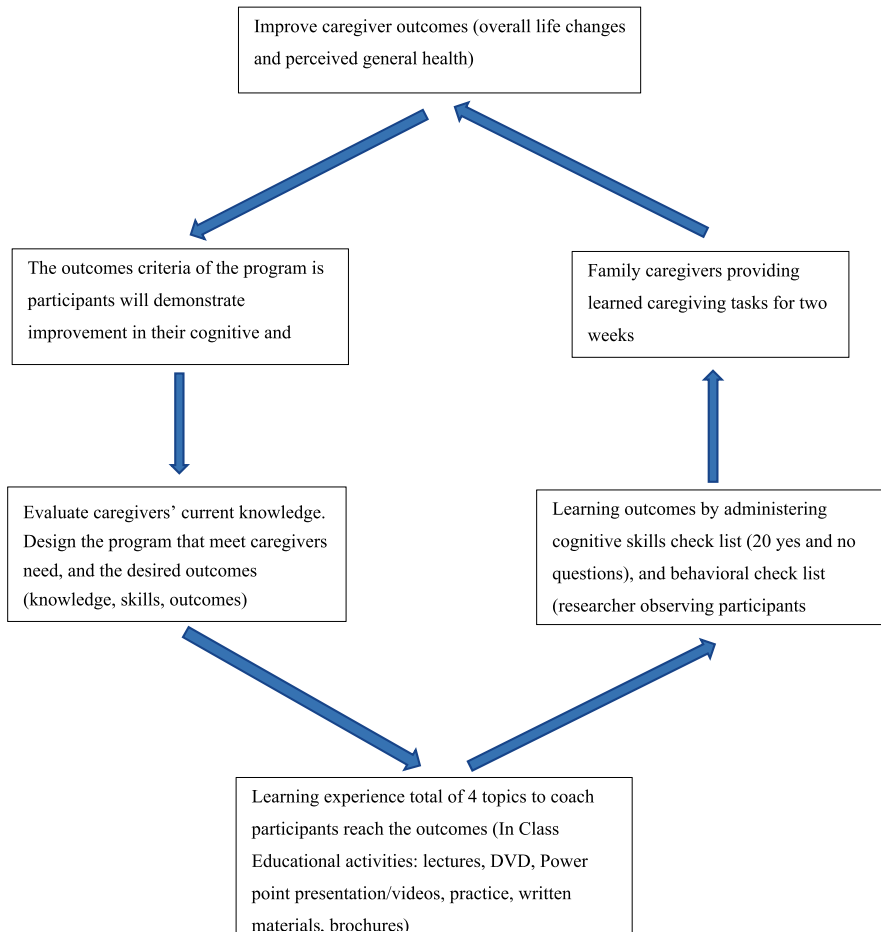


Fig. 1. An illustration of Caregiver Outcome-Based Learning.

the patient as a primary caregiver unpaid, 21 years or older, cared for the patient for at least a year, having a working phone, and providing the patient with the at-home care (activity daily living) and outside care activities such as transportation, shopping, and calling physicians.

2.4. The study setting

The Study was carried out in four out-patient hemodialysis facilities located in three urban cities in Jordan between April and August 2017. Three of the hemodialysis facilities were located in one city while the other facility was in a different city.

2.5. Instruments for data collection

Three instruments were used in this study to collect data pertained to this study. Caregivers' sociodemographic characteristics, the Oberst Caregiving Burden Scale (OCBS) and the Bakas Caregiving Outcome Scale (BCOS). The OCBS and BCOS were translated from English into Arabic in accordance with Guillemin et al. [12] proposed guidelines. A pilot study of $n = 10$ caregivers was conducted to assess the validity of the translated questionnaires.

2.5.1. Sociodemographic characteristics

The caregivers filled self-reported questionnaires including a socio-demographic form which was developed by the researcher. The socio-demographic questionnaire collected personal social data such as the caregiver age, gender, marital status, use of social media, and relationship to patients. Caregiver health issues such as headaches, heartburn, difficulty falling or staying asleep, and hypertension were also collected by the socio-demographic questionnaire.

2.5.2. Oberst Caregiving Burden Scale-difficult subscales

The OCBS – difficult subscale, a 15-item scale, was used to measure caregiver perceived burden associated with the performance of physical and emotional caregiving tasks [13]. The items are rated on a 5-point Likert scale ranging from non-difficult as score 1 to extremely difficult as score 5, in response to the difficulty of the task. Higher scores indicated increased caregiver burden. One more *dietary need* item was added since the patients are required to follow a renal diet which was not included in the total mean scores and SD analysis. The Cronbach alpha for the questionnaire as tested by Bakas et al. [14] was 0.71 and 0.90 from the study by Jessup et al. [15]. The Cronbach's alpha obtained for this study was 0.80. Scores were calculated by averaging each item of the difficulty subscales and averaging total scores achieving a mean score between 1 and 5.

2.5.3. Bakas caregiving outcomes scales (BCOS)

The BCOS, a 15-item questionnaire, was used to measure caregiver perceptions of their lives change as a result of caregiving [16]. The BCOS items were rated on a 7-point response scale with the responses ranging from 1 to 7, with a score of 1 as change for the worst and score of 7 as change for the best. A score higher than 4 indicates that the caregiver's perception of life has changed for the better [14]. The Cronbach's α was found to be 0.88 [15], 0.94 [17], and 0.88 for this study.

2.6. Informational and educational materials

The informational and educational intervention materials were developed by the researchers having APN background. The intervention included educating caregivers on diet and nutrition, food recipes, weight control, blood pressure monitoring, infection, fistula care, quinine catheter care, hygiene (skin), bleeding precaution,

recreation, medication, fall prevention, available resources, and involving other family members in patient care. The methods of teaching were lectures, small groups of four to six learning skills, return demonstration, DVD, and written materials. The written materials were developed at a 5th-grade reading level. A checklist of educational topics was developed. Two trained nurses volunteered to assist the researcher in ensuring that the checklist was ticked properly. The content validity of the information and educational intervention materials were confirmed by a nephrologist, two hemodialysis nurses, and a dietitian.

2.7. Intervention procedure

A room was reserved and set up in the participating hospital for education purposes. Two volunteer trained nurses were present at each of the teaching sessions. Each caregiver attended a one 4-h long education session scheduled in each dialysis unit. The education sessions were organized so that each session was attended by 12 or fewer participants.

2.8. Data collection

Caregivers who agreed to participate were assigned in groups to meet with the researcher at the hemodialysis unit prior to patient hemodialysis session. The researcher explained the goal of the research project, the consent forms, and the voluntary but beneficial participation in the study. All caregivers signed the consent forms and were assured of confidentiality. A pilot study was conducted on 10 caregivers using OCBS and BCOS. The data analysis of the first pilot indicated there were unclear items in both scales. The scales were reviewed by two experts so that items could be rephrased in the Arabic language. A second pilot study was conducted on different 10 clients and there was a marked improvement in the caregivers understanding of the items reflected by decreased requests for clarifications of statements' meanings and also by the data analysis of the scale. Time for filling the questionnaires was also estimated during the pilot studies which ranged between 8 and 10 min.

Caregivers recruitment and baseline data collection were conducted in April 2017. Implementation of the intervention program took place in three phases. In the first site, the two-day intervention programs for four groups were implemented between June 26th and 27th. In the other three sites, three-day intervention programs for six groups were affected between July 15th and 17th. An extra session was fulfilled on August 15th for caregivers who missed their assigned sessions. The socio-demographic questionnaire, OCBS, and BCOS were completed prior to the educational intervention program. Caregivers attended one educational session each. If the caregivers missed the assigned session they were allowed to pick another session, to ensure that none of the participants missed the education program.

The researcher presented a PowerPoint Presentation and a DVD on hemodialysis signs and symptoms that need immediate attention, hands-on fistula care, pulse location, palpitation, count, and blood pressure checking, renal diet, meal preparations, and discussed the information material handed to caregivers including a list of available resources and phone numbers to contact in case of emergencies. At the end of the program, participants completed the cognitive checklist. Evaluation of behavioral skills based on the checklist was conducted by observing participants performing learned skills going through simulation learning stations. The BCOS was completed again two weeks after completing the educational session to allow sufficient time for practicing the new skills. The caregivers dropped the completed questionnaire in a designated box placed at each dialysis unit.

2.9. Data analysis

Data were analyzed using the Statistical Package for Social Sciences (SPSS) version 21.0 Descriptive statistics were computed to describe caregiver and sociodemographic characteristics (mean, median, standard deviation, frequency, and percentage). Paired sample *t*-test was utilized to compare the pre-intervention and post-intervention scores for the BCOS.

2.10. Ethical consideration

Prior to data collection, permission was obtained from the research scientific board for each hospital authority included in the study. Permission was also sought and granted from the hospital managers of each outpatient hemodialysis unit.

3. Results

3.1. Sociodemographic characteristics

A total number of 169 unpaid family caregivers returned all filled questionnaires. The caregivers age ranged from 26 to 70 years ($M = 41.62$, $SD = 10.11$). The number of years in caregiving varied 1–15 years ($M = 4.10$, $SD = 2.50$). The movement time to the dialysis unit (round trip) ranged from 30 to 110 min ($M = 64.11$, $SD = 16.55$). Majority of the caregivers were female ($n = 94$, 55.6%). The other categorical characteristics of the caregivers are summarized in Table 1.

3.2. Oberst caregiving burden scale-difficulty subscale

Table 2 presents the OCBS scores for the family caregiver. Participants reported low levels of difficulty in Communication ($M = 2.02$, $SD = 0.71$), seeking information from doctors, nurses, Medical or nursing treatments ($M = 2.18$, $SD = 0.79$), coordinating

Table 2

Results for Obrest caregiving burden scale ($n = 169$).

Item	<i>M</i>	<i>SD</i>	<i>Mdn</i>	<i>Min</i>	<i>Max</i>
Communication	2.02	0.71	2	1	4
Seeking information from doctors, nurses	2.18	0.79	2	1	4
Medical or nursing treatments	2.21	0.72	2	1	4
Coordinating resources	2.22	0.87	2	1	5
Behavior problems	2.28	0.89	2	1	5
Assistance with mobility	2.51	0.86	3	1	5
Structuring/Planning activities	2.54	0.84	3	1	5
Providing transportation	2.65	0.96	3	1	5
Symptom monitoring	2.82	0.80	3	1	5
Tasks outside homes	2.87	0.82	3	1	5
Assistance with personal care	3.02	1.02	3	1	5
Emotional support	3.20	0.90	3	1	5
Household tasks	3.28	0.76	3	1	5
Managing finances	3.52	0.87	4	1	5
Finding caregiver to help	3.62	0.78	4	2	5
Dietary needs	3.92	0.83	4	2	5
Total Mean Score	2.73	0.23			

P.S Dietary needs was not included in the analysis.

resources ($M = 2.22$, $SD = 0.72$), and dealing with behavioral problems ($M = 2.28$, $SD = 0.87$). Participants reported moderate difficulties in assistance with mobility ($M = 2.51$, $SD = 0.86$), structuring/planning activities ($M = 2.54$, $SD = 0.84$), providing transportation ($M = 2.65$, $SD = 0.96$), symptom monitoring ($M = 2.82$, $SD = 0.80$), tasks outside homes ($M = 2.87$, $SD = 0.82$), assistance with personal care ($M = 3.02$, $SD = 1.02$), emotional support ($M = 3.2$, $SD = 0.90$), and household tasks ($M = 3.28$, $SD = 0.76$). Caregivers reported high level of difficulty in dietary needs ($M = 3.92$, $SD = 0.83$), managing finances ($M = 3.52$, $SD = 0.87$), and finding caregiver to help ($M = 3.62$, $SD = 0.78$). The overall scores indicated that caregiver burden was moderate ($M = 2.73$, $SD = 0.23$).

Table 1

Characteristics of caregivers ($n = 169$).

Characteristic	Category	<i>n</i>	%
Living arrangement	Lives with patient	89	52.7
	Lives within 50 m from patient	59	34.9
	Lives more than 50 m from patient	21	12.4
Economic Status	Comfortable	11	6.5
	Just enough	61	36.1
	Not enough	97	57.4
Marital Status	Single	43	25.4
	Married	126	74.6
Relationship to Patient	Daughter/Daughter-in-law	44	26.0
	Son	64	37.9
	Spouse	61	36.1
Caregivers knowledge of disease and management (diet/nutrition, weight control, medication, fistula care, symptoms recognition and management).	Good	15	8.9
	Average	48	28.4
	Poor	106	62.7
Caregiver educational level	12 grade	17	10.1
	2 years community college	60	35.5
	4 years college	69	40.8
	Graduate school	23	13.6
Number of Hemodialysis sessions	3 times a week 4 h long	141	83.4
	2 times a week 5 h long	28	16.6
Attended a class on Caregiving	Yes	0	
	No	169	100
Uses social media with friends and family	Educated yourself from the media	24	14.2
	Yes	128	75.7
Symptoms	No	41	24.3
	Headache	33	19.5
	Heartburn	86	50.9
	Difficulty falling or staying asleep	59	34.9
	Hypertension	45	26.6

3.3. Bakas caregiving outcomes scale

Table 3 presents the pre-intervention scores for the BCOS. The respondents used the full range of item scores from 1 to 7. Participants reported negative changes in time for social activities ($M = 2.28$, $SD = 0.90$). Participants reported lack of changes in financial well-being ($M = 2.88$, $SD = 0.83$), ability to cope with stress ($M = 2.98$, $SD = 0.84$), physical health ($M = 2.94$, $SD = 1.05$), future outlook ($M = 3.00$, $SD = 1.14$), emotional well-being ($M = 3.07$, $SD = 1.09$), time for family activities ($M = 3.08$, $SD = 0.88$), general health ($M = 3.12$, $SD = 0.79$), roles in life ($M = 3.30$, $SD = 0.84$), and relationship with friends ($M = 3.33$, $SD = 0.9$). Participants reported positive changes in physical functioning ($M = 3.61$, $SD = 1.08$), self-esteem ($M = 3.62$, $SD = 0.91$), relationship with family ($M = 3.67$, $SD = 1.01$), and relationship with the patient ($M = 4.05$, $SD = 1.01$). Overall, caregivers lives had changed for the worse ($M = 3.17$, $SD = 5.09$).

3.4. Pre-and post-educational measures

Table 4 presents pre and post-test measures of BCOS. The mean score for BCOS is lower prior to initiating the intervention as compared to the post-intervention scores. The post-intervention scores indicate that the information and educational intervention had a positive influence on the caregiving outcomes. A paired sample T-test result showed that the T values are significant at $p \leq 0.05$, indicating that the educational program had made a substantial positive impact on the caregiver outcomes.

4. Discussion

The study's findings provided insights on the level of caregiver's burden and the impact of the education intervention. In the current study, caregivers reported a moderate level of burden. Consistent with the current findings, previous studies on caregiving reported that caregivers were burdened [7,15,19]. Caregivers reported low burden in communicating, seeking information, administering treatment, coordinating resources, and behavioral problems. With the average caregiver experience being over 4 years, caregivers in the current study are likely to have enhanced their capability with time in performing the caregiving tasks, thus the low burden scale.

Dietary needs, managing finances and finding another caregiver to help were reported as the most challenging issues in the current

Table 3
Result for Bakas caregiving outcome scale ($n = 169$).

Item	M	SD	Mdn	Min	Max
Time for social activities	2.28	0.90	2	1	5
Level of energy	2.77	0.95	3	1	5
Financial well-being	2.88	0.83	3	1	5
Ability to cope with stress	2.90	0.84	3	1	5
Physical health	2.94	1.05	3	1	5
Future outlook	3.00	1.14	3	1	6
Emotional well-being	3.07	1.09	3	1	5
Time for family activities	3.08	0.88	3	1	5
General health	3.12	0.79	3	2	5
Roles in life	3.30	0.84	3	1	5
Relationship with friends	3.33	0.90	3	1	5
Physical functioning	3.61	1.08	4	1	6
Self-esteem	3.62	0.91	4	1	6
Relationship with family	3.67	1.01	4	1	6
Relationship with patient	4.05	1.01	4	1	7
Total Mean Score	3.17	5.09			

Table 4

Paired Sample *t* Test for the differences between the pre-and post-test for Bakas Caregiving Outcomes Scale ($n = 169$).

Items	Measure	M	SD	t	P
Self-esteem	Post	5.19	0.87	17.43	<0.01
	Pre	3.64	0.89		
Physical health	Post	5.23	0.69	25.25	<0.01
	Pre	2.92	1.06		
Time for family activities	Post	4.97	0.91	21.47	<0.01
	Pre	3.13	0.84		
Ability to cope with stress	Post	3.97	0.91	12.37	<0.01
	Pre	2.91	0.83		
Relationship with friends	Post	4.77	0.96	17.43	<0.01
	Pre	3.31	0.89		
Future outlook	Post	4.61	1.00	15.41	<0.01
	Pre	2.97	1.13		
Level of energy	Post	4.12	0.97	16.99	<0.01
	Pre	2.76	0.96		
Emotional well-being	Post	4.18	1.19	12.42	<0.01
	Pre	3.06	1.09		
Roles in life	Post	4.43	1.03	12.73	<0.01
	Pre	3.30	0.84		
Time for social activities	Post	3.65	1.20	15.07	<0.01
	Pre	2.30	0.91		
Relationship with family	Post	4.96	1.12	14.98	<0.01
	Pre	3.68	1.01		
Financial well-being	Post	3.99	1.00	13.64	<0.01
	Pre	2.86	0.83		
Relationship with patient	Post	5.19	0.98	12.19	<0.01
	Pre	4.05	0.99		
Physical functioning	Post	4.80	1.04	12.23	<0.01
	Pre	3.65	1.07		
General health	Post	4.23	1.03	12.92	<0.01
	Pre	3.11	0.79		

study. Patients receiving hemodialysis need a special diet to limit the buildup of waste and fluids in the patient's body. The recommended hemodialysis diet is a challenge to caregivers, in preparation and adherence, especially where the caregiver lacks the necessary knowledge [6]. Previous research also reported that patients and caregivers who had inadequate income had a higher burden score in financial management [5,20]. The intensive caregiving tasks could discourage other family members from assisting, therefore, caregivers find it difficult to get assistance from other people in providing care for the patients. A study by Shah et al. [21] established that although family caregivers were moderately burdened, the strong family ties would not allow family caregivers to give up the care of the family member to someone else. This could explain the reason caregivers in the current study listed high burden levels in finding a qualified or an experienced family member to help with patient care.

Prior to the educational intervention, caregivers reported negative life changes. Post-intervention, caregivers reported substantial positive caregiving outcomes. Caregivers reported enhanced self-esteem, outlook, time management skills, and energy levels. Educational programs for caregivers increased their knowledge of the diseases, thus improving their skills and ability to offer quality care while caring for themselves [18,19]. Previous studies also found that family caregivers lack sufficient information regarding the disease process, home care of the patients, nutrition, and medication therapy [20].

Educating caregivers and providing caregivers with the necessary skills to enhance their caregiving activities results in less exhaustion and a positive outlook [6]. With the necessary skills and support, caregivers' physical and mental health is not negatively affected by their caregiving tasks, facilitating the provision of quality care to the patients and promoting positive health

outcomes. In a study by Honea et al. findings established caregiving as complex and demanding and requires multidimensional support that incorporates emotional, spiritual, psychological, and physical domains [22]. In line with the current study, Farahani et al. indicated that home education programs are effective in reducing caregivers' stress, thus improving their quality of life [19].

Limited studies have investigated the effects of the educational program on caregivers' burden using one group or two group designs. Mollaoglu et al. [18] used one group design to assess the effectiveness of the educational program on caregivers providing care among patients receiving hemodialysis. The established that the educational program applied was effective in reduction of the caregivers' burden severity. The current study is different in that the BCOS was used, which allowed the caregivers to express the positive changes in their lives following the intervention.

Farahani et al. [19] conducted a study in Iran using a two-group prospective study design to examine educational program's effects on family caregivers. The study established that burden mean score of the interventional group in comparison to the control group was significantly lower. Similarly, Nejad et al. [23] used a two-group design study in Iran on caregivers for a patient diagnosed with cancer to compare caregiver strains scale. After completing the educational intervention program, the score was significantly higher in the intervention group.

The sample size used in the present study is four times larger, and therefore, a generalization of the findings is possible. The educational program offered to family caregivers and will likely achieve success and caregivers will know what caregiving tasks they're able to handle. Nurses will also be attracted to an OBL theoretical framework because of the distinctive learning outcomes after caregivers complete the educational program. To implement an OBL model, it is best to start with general learning outcomes, then program intended learning outcomes. The education session is based on caregivers' assessment and evidence-based practice guidelines. Teaching strategies are aligned with program outcomes and educators taking into consideration; that caregivers are the center of the educational process to achieve better outcomes. The role of the nurse is being a facilitator to achieve caregiver intended outcomes and re-assessing caregiving outcomes.

Several studies have focused on caregiver burden for caregivers attending to chronically ill patients. However, few studies have focused on strategies to alleviate caregivers' burden and increasing positive caregiving outcomes. The current study identifies caregiver burden from caring for chronic disease patients, which APNs can utilize and implement interventions aimed at easing caregiver burden and improving caregiving outcome. The current study introduces educational programs for caregivers focused on improving caregiving outcomes. APNs can educate caregivers on basic caregiving knowledge, thus improving their health and quality of life. The study model can be generalized to caregivers caring for elderly patients, children, and young adults with chronic diseases and disabilities.

Using the theoretical framework of the study, further research on caregivers' burden can be conducted to establish the levels of burden in caring for patients with different diseases and disabilities. Future research should explore the long-term effectiveness of educational programs in improving caregiving outcomes and alleviating caregivers' burden. A decrease and increase in the number of educational sessions to warrant positive caregiving outcomes should also be explored in future research.

5. Limitations

The study was conducted on caregivers of patients receiving hemodialysis, which is a long-term condition. The study findings

are limited to caregivers taking care of long-term condition patients and may not be generalized to patients with short-term health conditions. The effects of the intervention were tested short-term. The study is, therefore, limited to short-term impacts of the intervention. The other limitation of the one-group pre-test post-test study include the threats to internal validity. The use of pre-test post-test design may not allow for accurate assessment of the program's effectiveness because it lacks a control group for comparison.

6. Conclusions

The study's findings established that caregivers were moderately burdened and reported negative caregiving outcomes, and established the educational program as effective in improving caregiving outcome. The study's findings can be used by hospital policy makers to instigate the effectiveness of mandatory training for chronic patients' caregivers to ease their burden, and improve caregiving outcomes, thus improving the patients' health.

Notes

The author confirms that the study was not supported by any grant and there is no conflict of interest.

Acknowledgments

The author gives thanks to the patients, the caregivers, staff nurses and administration for their cooperation.

References

- [1] Reinhard SC, Levine C, Samis S. Home alone: family caregivers providing complex chronic care. Washington, DC: AARP Public Policy Institute; 2012 [oct].
- [2] AARP Public Policy Institute. Report: caregiving in the U.S. 2015. Accessed from, <https://www.aarp.org/content/dam/aarp/ppi/2015/caregiving-in-the-united-states-2015-report-revised.pdf>.
- [3] Bayoumi MM. Subjective burden on family carers of hemodialysis patients. *Open J Nephrol* 2014;4(02):79.
- [4] Mashayekhi F, Pilevarzadeh M, Rafati F. The assessment of caregiver burden in caregivers of hemodialysis patients. *Mater sociomed* 2015;27(5):333–6.
- [5] Subhashini N, Indira DA. Assess the burden among caregivers of patients undergoing hemodialysis in tertiary care hospital, Nellore. *Int J Applied Res* 2016;2(4):559–61.
- [6] Revenson T, Griva K, Luszczynska A, Morrison V, Panagopoulou E, Vilchinsky N, et al. *Caregiving in the illness context*. 1st ed. Palgrave macmillan UK. 2016.
- [7] Alnazly EK. Burden and coping strategies among Jordanian caregivers of patients undergoing hemodialysis. *Hemodial Int* 2016;20(1):84–93.
- [8] Creedle C, Leak A, Deal AM, Walton AM, Talbert G, Riff B, Hornback A. The impact of education on caregiver burden on two inpatient oncology units. *J Canc Educ* 2012;27(2):250–6.
- [9] Martín-Carrasco M, Domínguez-Panchón AI, González-Fraile E, Muñoz-Hermoso P, Ballesteros J. Effectiveness of a psychoeducational intervention group program in the reduction of the burden experienced by caregivers of patients with dementia: the EDUCA-II randomized trial. *Alzheimer Dis Assoc Disord* 2013;28(1):79–87.
- [10] Isenberg KB, Trisolini M. Information needs and roles for family members of dialysis patients. *Dial Transplant* 2008;37(2):50–7.
- [11] Lixun W. Evaluation of outcome-based learning in an undergraduate English language program. *Res High Educ J* 2013;20. Retrieved from, <https://files.eric.ed.gov/fulltext/EJ1064620.pdf>.
- [12] Guillemin F, Bombardier C, Beaton D. Cross-cultural adaptation of health-related quality of life measures: literature review and proposed guidelines. *J clinic epidemiol* 1993;46(12):1417–32.
- [13] Bakas T, Austin JK, Jessup SL, Williams LS, Oberst MT. Time and difficulty of tasks provided by family caregivers of stroke survivors. *J Neurosci Nurs* 2004;36(2):95–106.
- [14] Bakas T, Champion V, Perkins SM, Farran CJ, Williams LS. Psychometric testing of the revised 15-item Bakas caregiving outcomes scale. *Nurs Res* 2006;55(5):346–55.
- [15] Jessup NM, Bakas T, McLennon SM, Weaver MT. Are there gender, racial or relationship differences in caregiver task difficulty, depressive symptoms and life changes among stroke family caregivers? *Brain Inj* 2015;29(1):17–24.

- [16] Bakas T. Bakas caregiving outcomes scale. In encyclopedia of quality of life and well-being research. Springer Netherlands; 2014. p. 319–21.
- [17] Denno MS, Gillard PJ, Graham GD, DiBonaventura MD, Goren A, Varon SF, Zorowitz R. Anxiety and depression associated with caregiver burden in caregivers of stroke survivors with spasticity. *Arch Phys Med Rehabil* 2013;94(9):1731–6.
- [18] Mollaoglu M, Kayataş M, Yürügen B. Effects on caregiver burden of education related to home care in patients undergoing hemodialysis. *Hemodial Int* 2013;17(3):413–20.
- [19] Farahani M, Ghane G, Sydfatemi N, Hagani H. Effect of educational program on the burden of family caregivers of hemodialysis patients. *Evidence Based Care J* 2016;6(1):7–18.
- [20] Tong A, Sainsbury P, Craig JC. Support interventions for caregivers of people with chronic kidney disease: a systematic review. *Nephrol Dial Transplant* 2008;23(12):3960–5.
- [21] Shah HB, Atif I, Rashid F, Babar MW, Arshad F, Qamar W, et al. Assessment of caregiver burden of patients receiving dialysis treatment in Rawalpindi. *J Pakistan Med Assoc* 2017;67(10):1498–501.
- [22] Honea NJ, Colao DB, Somers SC. Putting Evidence into Practice: nursing assessment and interventions to reduce family caregiver strain and burden. *Clin J Oncol Nurs* 2008;12(3):507–16.
- [23] Nejad ZK, Aghdam AM, Hassankhani H, Sanaat Z. The effects of a patient-caregiver education and follow-up program on the breast cancer caregiver strain index. *Iran Red Crescent Med J* 2016;18(3):e21627.