

## Caregivers Burden of Chronic Medical Illnesses in Older Patients

Hashim Balubiad<sup>1</sup>, Qamar Khojah<sup>2</sup>, Rawan AlDahash<sup>2</sup>, Sara AlMedlej<sup>2</sup>,  
Shorowk AlRumaihi<sup>2</sup>, Alaa Althubaiti, PhD<sup>2</sup>

<sup>1</sup>Department of Medicine, King Abdulaziz Medical City, Riyadh, Saudi Arabia

<sup>2</sup>College of Medicine, King Saud bin Abdulaziz University for Health Sciences, Riyadh, Saudi Arabia

### Abstract

*A cross-sectional study was conducted with 150 adult caregivers of patients with chronic illnesses in three tertiary medical centers in Riyadh 2015. This study addresses different aspects of burden placed on caregivers of chronic older patients.*

*Caregivers who fulfilled the inclusion criteria, were approached by consecutive sampling. Participants were interviewed using an Arabic version of the Montgomery Borgatta Burden Measure Scale. The scale measures the Subjective (SB), Objective (OB) and Stress Burden (StB).*

*The results showed that the SB, OB and StB were found to be mild in the sampled population ( $7.7\pm 3.7$ ,  $14.2\pm 3.4$ , and  $9.05\pm 4.2$ ) respectively, compared to reference values (13.5, 23 and 15) of high burden. The StB was found to be higher in females than in males ( $9.86\pm 4.56$  vs.  $8.44\pm 3.89$  respectively,  $p=0.041$ ). Furthermore, nurses were found to have a greater SB compared to relatives ( $11.4\pm 5.29$  vs.  $7.58\pm 3.34$  respectively,  $p=0.002$ ). Analysis also showed that the caregivers who were employed elsewhere had lower StB, and OB ( $p=0.004$ , and  $0.034$ , respectively). No other associations were found.*

*In Conclusions, caregivers of chronically ill patients experienced a distinct level of burden while providing care. Socio-demographic factors were predictors of the level of burden.*

**Keywords:** Caregiver, Impact, Objective Burden, Stress Burden, Subjective Burden

### 1. Introduction

Caregiving is one of the most common difficulties facing families with chronically ill members. These families often experience chronic stress referred to as caregiver burden, which is the emotional and physical complications that affect the caregiver who is taking care of a relative or a friend [1]. An article about the demand and difficulty in older adult spousal caregivers of post coronary artery bypass grafting CABG surgery patients [2], using the caregiving burden scale among 35 caregivers, reported that during providing assistance in caregiving activities like transportation, additional household tasks and providing emotional support, caregivers perceived the tasks to be demanding rather than being difficult [2].

A nationwide survey of patient family caregiver dyads in Korea [3] was conducted to assess the prevalence and predictors of anxiety and depression among family caregivers of cancer patients. The survey was conducted with 897 family caregivers. Hospital anxiety and depression scale was used. It reported that there was an increase in anxiety among family caregivers who were younger, were caring for male patients, or had a low quality of life. It is also reported that being unemployed during caregiving, being the spouse of the patient, and having a lower quality of life are associated with depression among family caregivers [3]. Another study looked at caregivers and patients sociodemographic and health characteristics associated with caregiver burden in patients above 60 having one of this disease: advanced cancer, heart failure, and chronic obstructive pulmonary disease COPD [4].

After the medical record review of patients and a 10-items subset of the Zarit Burden Inventory (ZBI) for caregivers, results were: no change in the overall burden over time, no difference in caregiver burden related to any specific diagnosis and the majority of the caregivers, regardless of diagnosis, reported psychological distress. Also, regardless of diagnosis or duration of caregiving, the need for assistance with activities of daily living ADLS was mostly correlated with caregiver burden [4]. Furthermore, a study from the department of Gerontology of Nebraska University, including spouses and adult child caregivers of patients with chronic illness has shown that the burden is equivalent in multidimensional construct between the two groups. The study has included three categories of burden: Stress burden, which is tension and anxiety, relationship burden and the objective burden resulting from caregiving [5].

Another study was conducted in Chang Gung University, Taiwan among 447 caregivers of terminally ill cancer patients using depression scale [6]. Caregivers were found to follow distinct depressive symptom trajectories while providing end of life care. Such effects extend into bereavement with adjustment difficulties and increased morbidity and mortality. Most of the studies showed that there is an international burden among caregivers associated with different demands and difficulties regardless of the diagnosis and the duration [6]. It has been noticed that estimating caregiving burden was beneficial for healthcare workers in other populations, in order for physicians to understand the stresses facing the caregivers and the patients [6].

No similar study has been conducted in Saudi Arabia. This study will be the first to focus on the caregivers' complications. In Saudi Arabia, there are different characteristics of caregivers of chronic medical illnesses in older patients that are different from those worldwide based on religion and culture differences. Because of psychosocioeconomic effects on a caregiver, it is important to estimate the prevalence of the problem in Riyadh to identify burden of the problem and direct attention of health care system.

## **2. Materials and Methods**

This cross-sectional study was conducted from January to March 2015 at three hospitals in Riyadh, Saudi Arabia. These are Specialized Medical Center (SMC), Riyadh Care Hospital (RCH) and King Fahad Hospital in King Abdulaziz Medical City (KAMC). Participants in the study were male and female adult spouse, adult children (18 and above), housemaids, drivers, and house care nurse caregivers. Caregivers with psychiatric problems or those who refused to participate in the study were excluded. Out of 500 patients, which is the estimated number of geriatric patients in these three hospitals, the sample was estimated to be 150 based on a 95 percent confidence level and 80 percent power, considering the expected outcome to be 70% with a margin of error of  $\pm 10\%$ . In total, 50 patients were included from each of the three hospital settings by convenience sampling. The study was approved by the institutional review boards of King Abdullah International Medical Research Center.

### **3. Measures**

We used the Montgomery Borgatta Burden Scale [7,8] questionnaire regarding caregiver burden. This scale has been used in many similar pieces of research in its original English form [5] and translated/validated to French [9]. The questionnaire measures three aspects of burden in a 5-item Likert response format (1 = Not at all to 5 = A great deal). These are subjective (SB), objective (OB), and stress burden (StB). The subjective burden, the perception of responsibilities and demands of the patient by the caregiver, measured by five items and has a score range of 5 to 25. The objective burden, the disruption of caregiver's life, measured by six items and has a score range of 6 to 30. The stress burden, the sentimental feelings of the caregiver toward responsibilities, measured by five items and has a score range of 5 to 25. Higher summed scores of each subscale suggesting higher burden. According to previous works of literature [10], high objective, subjective, and demand burden are noticed when the summed scores of each subscale are greater than or equal to 23, 13.5, and 15 respectively.

We developed an Arabic version, which is equivalent to the original English version. The translation process consisted of four steps: forward translation, backward translation, preliminary test and field test. The forward translation from English to Arabic was performed by two English translators independently, both of whom were fluent

in English. The two drafts were then discussed among the research group that included a geriatric consultant, and four medical students. The two drafts were compared and a single version that is a combination of the two drafts was established by choosing the equivalent items compared to the original English version. Backward translation from Arabic to English was performed by a translator who had no access to the original version of Montgomery Borgatta caregiver burden scale. The backward version was compared with the original one by a team of the principal investigator and the co-investigators. Any disaccord or inaccuracy was detected by the team had been corrected to assure equivalence. The second Arabic version was then yielded. After the translation, the questionnaire was administered to six volunteered caregivers to evaluate its clarity. Volunteers were allowed to ask questions about the items on the questionnaire. After one week, the questionnaire was distributed again for the same contributors. The Arabic version of the Montgomery scale was finalized to be field tests in the current study. The internal consistency or Cronbach's alpha for the different aspects of Montgomery scale has ranged from 0.76 to 0.89.

#### 4. Statistical Analysis

Data are presented as mean  $\pm$  standard deviation (SD) for continuous variables, and percentages for categorical variables. The outcome (burden) was compared between the subjects using students' t-test or one-way analysis of variance (ANOVA) for the numerical variables. All statistical tests were considered significant at  $p < 0.05$ . Data were analyzed using the SPSS database (IBM SPSS Statistics, SPSS Inc., Chicago IL).

### 5. Results

#### 5.1 Subject characteristics

All the 150 potential caregivers were recruited. The mean age of caregivers of the chronically ill patients was  $35.4 \pm 11.4$  years (range, 17-79 years). The majority of these caregivers were males 85 (65.7%), and 65 (43.3%) were female. Of the 150 caregivers, 90 (60%) were employed and 60 (40%) were unemployed, 43 (28.7%) were single, 93 (62%) were married, 14 (9.3%) were either divorced or widowed. In regard to educational qualifications of caregivers, 21 (14%) were below elementary, 17 (11.3%) elementary, 15 (10%) intermediate, 50 (33.3%) secondary and 47 (31.3%) university and above.

Of the 150 participants, 97 (64.7%) of caregivers were relatives, 14 (9.3%) were home nurses and 39 (26%) were either housemaids or drivers. When caregivers were recruited into this study and completed the baseline questionnaires, 67 (44.7%) have been taking care of the patient for less than six months, 26 (17.3%) have been taking care of them from 6-12 months, and 57 (38%) have been taking care of them for more than 12 months. Among these, 41 (27.3%) are taking care of the patient for 12 hours or less per day and 109 (72.7%) for more than 12 hours per day. The diagnosis of the patients included in this study were mostly unknown diagnosis 47 (31.3%), followed by 41 (27.3%) of neurological diseases, 15 (10%) of multiple diagnoses, 13 (8.7%) respiratory diseases, Cancers 11 (7.3%), Others 11 (7.3%), Genitourinary Diseases 7 (4.7%), GI and hepatological diseases 3 (2.0%), and the lowest were cardiovascular diseases 2 (1.3%). The characteristics of the study samples are shown in Table 1.

**Table 1. Demographic characteristics of caregivers and patients.**

	Mean $\pm$ SD or N (%)	Range
Gender		
Male	85(65.7%)	
Female	65(43.3%)	
Age, years	$35.4 \pm 11.4$	17-79
Status		
Single	43(28.7%)	
Married	93(62%)	
Others (Divorced/ Widow)	14(9.3%)	
Relationship to the patient		

Relatives	97(64.7%)	
Nurse	14(9.3%)	
Other (housemade/driver)	39(26%)	
Qualifications		
Below elementary	21(14%)	
Elementary	17(11.3%)	
Intermediate	15(10%)	
Secondary	50(33.3%)	
University and above	47(31.3%)	
Employment		
Employed	90(60%)	
Unemployed	60(40%)	
Duration of caregiving		
< 6 months	67(44.7%)	
6-12 months	26(17.3%)	
> 12 months	57(38%)	
Caregiving hours per day		
≤ 12 hours	41(27.3%)	
> 12 hours	109(72.7%)	
Diagnosis of the patient		
Cancers	11(7.3%)	
Cardiovascular diseases	2(1.3%)	
Neurological diseases	41(27.3%)	
Respiratory diseases	13(8.7%)	
GI and hepatological diseases	3(2.0%)	
Genitourinary Diseases	7(4.7%)	
Others	11(7.3%)	
Multiple Diagnoses	15(10.0%)	
Unknown	47(31.3%)	
Total number of caregivers (N)= 150.		

### 5.2 Caregiver's burden

The mean  $\pm$  SD scores of subjective burden, objective burden, and stress burden were  $7.7\pm 3.7$ ,  $14.2\pm 3.4$  and  $9.05\pm 4.2$ , respectively. According to the previously mentioned ranges, the overall burden is considered to be no to mild burden in our Saudi community.

In the SB, caregivers reported higher attempts for manipulation by the patient than any other aspect ( $1.71\pm 1.15$ ) (Table 2). Also, according to Table 3, caregivers had less time for themselves compared to other aspects of the OB ( $2.81\pm 1.40$ ). Caregiving was mostly associated with higher rates of worrying compared to other items in the StB ( $1.98\pm 1.31$ ) (Table 4).

**Table 2. Items from subjective burden scale.**

Subjective burden	Not at all	A little	Moderately	A lot	A great deal	Overall mean
	N(%)	N(%)	N(%)	N(%)	N(%)	
Increased attempts by your relative to manipulate you?	99(66)	20(13.3)	12(8)	14(9.3)	5(3.3)	1.71 $\pm$ 1.15
Increased the number of unreasonable requests made by your relative?	100(66.7)	19 (12.7)	17(11.3)	11(7.3)	3 (2)	1.65 $\pm$ 1.06

Caused you to feel that your relative makes demands over and above what he/she needs?	105(70)	15(10)	10(6.7)	14(9.3)	6(4)	1.67±1.18
Made you feel you were being taken advantage of by your relative?	129(86)	10(6.7)	4(2.7)	4(2.7)	3(2)	1.28±0.81
Caused conflicts with your relative?	124(82.7)	12(8)	4(2.7)	8(5.3)	2(1.3)	1.35±0.87

**Table 3. Items from objective burden scale**

<b>Objective burden</b>	<b>Not at all N(%)</b>	<b>A little N(%)</b>	<b>Moderately N(%)</b>	<b>A lot N(%)</b>	<b>A great deal N(%)</b>	<b>Overall mean</b>
Decreased time you have to yourself?	737(24.)	32(21.3)	24(16)	36(24)	21(14)	2.81±1.40
Kept you from recreational activities?	59(39.3)	30(20)	15(10)	32(21.3)	14(9.3)	2.41±1.42
Caused your social life to suffer?	105(70)	18(12)	9(6)	12(8)	6(4)	1.64±1.14
Changed your routine?	40(26.7)	31 (20.7)	14(9.3)	53(35.3)	12(8)	2.77±1.38
Left you with almost no time to relax?	69(46)	35 (23.3)	21(14)	18(12)	7(4.7)	2.06±1.22
Given you little time for friends and relatives?	46(30.7)	35 (23.3)	23(15.3)	36(24)	10(6.7)	2.53±1.32

**Table 4. Items from stress burden scale.**

<b>Stress burden</b>	<b>Not at all N(%)</b>	<b>A little N(%)</b>	<b>Moderately N(%)</b>	<b>A lot N(%)</b>	<b>A great deal N(%)</b>	<b>Overall mean</b>
Created a feeling of hopelessness?	96(64)	22(14.7)	9(6)	18(12)	5(3.3)	1.76±1.19
Made you nervous?	100(66.7)	28(18.7)	11(7.3)	6(4)	5(3.3)	1.59±1.01
Depressed you?	94(62.7)	21(14)	12(8)	13(8.7)	10(6.7)	1.83±1.27
Made you anxious?	76 (50.7)	35(23.3)	21(14)	14(9.3)	4(2.7)	1.9±1.12
Caused you to worry?	84 (56)	24(16)	11(7.3)	23(15.3)	8(5.3)	1.98±1.31

Stress burden levels were significantly higher in female caregivers compared to male caregivers (9.86±4.56 vs. 8.44±3.89, P=0.041). No other significant difference was found between male and female caregivers in regard to the

subjective and objective burden. Table 5 shows subjective, objective, stress and overall burden between male and female caregivers.

**Table 5. Comparison of gender and employment status in caregiver burden scale.**

Burden Type	Gender		P value	Employment		P value
	Male	Female		Employed	Unemployed	
Subjective burden	7.52±3.88	7.85±3.49	0.588	7.43±3.32	8±4.24	0.385
Objective burden	14.32±5.51	14.11±5.25	0.814	13.5±5.58	15.4±4.91	0.034
Stress burden	8.44±3.89	9.86±4.56	0.041	8.24±3.39	10.27±5.06	0.004
Overall burden	30.3±11.51	31.82±11.4	0.415	29.1±10.6	33.6±12.4	0.018

Objective burden levels, stress burden scores, and overall burden were significantly higher in non-employed caregivers compared to employed caregivers (P=0.034, 0.004, and 0.018, respectively). Employed patients have the objective burden of 13.5±5.58, stress burden of 8.24±3.39, and overall burden of 29.14±10.6 compared to non-employed caregivers, 15.4±4.91, 10.27±5.06, and 33.6±12.4, respectively. Table 3 shows a comparison between employed and non-employed caregivers.

A significant difference was found between relationship status in overall caregiver burden (P=0.022) and subjective burden (P<0.001). Post Hoc analysis shows that a significant difference was found between nurse and other caregivers in regard to the overall caregiver burden (36.64±14.39 vs. 27.36±10.62, P=0.024). Also, in regard to the subjective burden significant difference was found between nurse and relatives (11.4±5.28 vs. 7.58±3.33, P=0.002). There was no significant association between social status, education, duration of caregiving, caregiving hours and burden of caregivers.

## Discussion

In the present research, the aim is to evaluate the burden of chronic medical illnesses on caregivers in Riyadh. Caregiver burden has been assessed in many countries around the world and being used for an intervention to provide resources and support for this important growing population. In Saudi Arabia, there is a lack of similar studies to assess the burden, this is one of the reasons why we are behind in helping this population. We assumed that our community is suffering from caregiving burden that needs to be assessed to help guide the support services.

The overall burden is considered to be no to mild burden in our Saudi community. This result is similar to a previous study that measured the caregiver burden in Thailand [4]. The study results showed that females have a higher subjective burden because they overvalue the perception of caregiving and furthermore they have higher stress burden and this might be reflecting the fact that females are more emotional than males. On the other hand, males were found to have a higher objective burden which is understandable because of higher life responsibilities of men in our society, so caregiving is an additional task on top of their usual working roles. In a previous study, males were found to have a higher risk for anxiety [3].

The results of comparing employed to unemployed caregivers showed that unemployed caregivers have a higher burden in all aspects, this could be the contribution of multiple reasons; some of the unemployed actually quit their jobs to take care of their relatives which left them with no other things to do besides the caring responsibilities which might lead to developing depression and frustration. On the other hand, some of the employed are using the help of others to take care of their relatives instead of them most of the time. This result is similar to one previous study that found caregivers who were previously employed and then lost their job to have a higher risk for anxiety [3].

One of the populations' most vulnerable to burden caused by providing long-term care is nurses, because they are not only responsible for the medical condition of the patient but also have to deal with the family concerns and the medical staff. On the other hand, relatives have the lower burden, because our Islamic culture highly values the filial duty and children have strong bonds with their parents as they were raised to sense this obligation. Household keepers have the lowest burden, as they rarely get emotionally involved. The duration of caregiving per day has also affected the subjective burden on caregivers, those who consume <12 hours with the patients were found to have more burden, which could be the result of their misleading feeling of the real patient demand caused by less time spent with them. Most of the caregivers did not know the diagnosis of the patients, which could be because doctors do not disclose information to the caregivers or the caregivers do not understand the information given; it can also be due to many caregivers taking care of the same patient.

For caregivers of older patients with chronic illnesses, the caregiving demand was found to be higher in females and with longer duration of caregiving. These findings were similar to the findings of prior studies of caregiver burden [11]. In literature, the most burdens were associated with caregivers who are employed and with a close relationship to the patient [3,12,13]. However, in this study, caregivers were found to be non-employed, or house care nurses.

The study has some limitations; the distance from the patient's and caregiver's residence to the hospitals was not measured which has shown to affect the burden in other studies [14]. Also, in this study attention was not paid regarding the psychological aspect of the patient and caregiver, i.e. Depression and anxiety which was found to be high in one study [3], and depressive symptoms have shown to affect the caregiving burden in different studies, like among caregivers of patients on hemodialysis [15], and patients with schizophrenia [1], owing to the fact that the quality of caregiving and the patient health is highly affected by the psychology of both of them. An important assessment measure of the level of independence of the patient that is the activity of the daily living (ADLs), which has shown in a previous study to have an effect on the objective burden was not assessed in our sample. The relation of age and gender of the patient with the degree of burden, which could be important affecting variables were not included in our study.

In summary, it was found that there is mild to no caregiving burden in our Saudi community. Objective burden was of the most demanding aspects of caregiving. Females are suffering more from caregiving burden. In addition, hours of caregiving, unemployment or working as a nurse are other highly ranked aspects contributing to the burden. It is recommended that more researches to be done in this field to clarify the extent of burden caregivers are facing and its aspects. Also, more efforts should be subjected to those people who care for their sick relative or employee and attempts should be made to provide a better environment for them.

## **Conclusion**

Caregivers of chronically ill patients experience a distinct level of the burden while providing end-of-life care. Socio-demographic factors were predictors of the level of burden. It is recommended to conduct further researches in this field, especially in developing countries and our Middle East area to estimate the burden and its aspect. Furthermore, efforts should be made to help those caregivers cope and provide a better supportive environment for them.

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