

## Research Article

# Assessment of the Perceived Burden of Care and Quality of Life among Family Caregivers of Patients Diagnosed with chronic Illnesses at Home Health Care Centers

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### Abstract

**Background:** A Caregiver burden is a multi-layered phenomenon involving various factors for both patients and caregivers. It is imperative that the needs and concerns of the caregiver are not forgotten or neglected in the rush to provide greater comfort for the person with the illness.

**Purposes:** This study aimed to assess the perceived burden of care and quality of life among family caregivers of patients diagnosed with chronic illnesses in home care centers at Jeddah.

**Design:** The study used descriptive cross-sectional correlation design. The study employed simple random sampling strategy to recruit 390 family caregivers from the home care center. The study employed the Zarit burden of care and Short form-36 Quality of life scales.

**Results:** The results of the study showed that family caregiver of patient with mental illness were experienced high burden of care compared with other family caregivers. In addition, they were also reported the poorest quality of life compared with caregivers of patient

diagnosed with cardiac or envious system disorder. Additionally, they reported poor quality of life scores, namely in physical and psychological dimension. The results indicated that family caregivers who were females, unemployed, less education were more likely to report negative impact of caregiving tasks.

**Keywords:** Burden of care; Quality of life; Family caregivers; Chronic illnesses

### Background

Family caregiver burden literature is extensive, and much is known regarding the toll these caregivers sustain while caring for a family member [1]. Historically, the measurement of caregiver burden has focused on global challenges of the family caregiver role including psychological, physical, financial, or time burden while caring for a family member [2]. Generally, caregiver burden has been measured holistically making it difficult for health care providers to determine specific interventions needed to help caregivers. More recently, researchers of family caregivers have suggested moving from these global conceptualizations and measurement of family caregiver burden to more specific foci. For example, given (2015) recommended that researchers move from global perspectives to more specific conceptualizations of family caregiver burden in order to better understand, measure, and tailor interventions to assist family caregivers. A specific measure of caregiver burden often overlooked and underestimated within these global measurements of caregiver burden, is the role of providing transportation by a family caregiver [2]. Coordinating transportation for a family member to primary health care providers, physical therapists, nutritionists, grocery stores, pharmacies, entertainment, and family outings may all be part of a family caregiving responsibility and in turn, contribute to caregiver burden. Additionally, physical and mental impairments of a family member may further contribute to transportation difficulties for family caregivers [3].

According to Sabzevari and Nematollahi [4] “Caregiver burdens is a multi-layered phenomenon involving various factors for both patients and caregivers”. Professional healthcare providers should thoroughly assess the caregiver’s life and lifestyle to ensure the caregiver is able to meet the needs of patients with Alzheimer’s disease. Additionally, it may become imperative for the healthcare provider to understand the impact the family member’s illness may have on a caregiver’s life. The impact may come from the patients’ illness, injury, or age-related diagnosis. The pressure to provide care can be overwhelming for the spouse, parent, siblings, or healthcare professionals. If caregivers lack the tools necessary to adequately care for their loved ones, negative behaviors can arise including abuse, neglect, or even death from the burden or strain [5]. It is imperative that the needs and concerns of the caregiver are not forgotten or neglected in the rush to provide greater comfort for the person with the illness. It is also necessary for the healthcare provider to address the concerns and needs of the caregiver so that the outcome of the patient’s care would be positive [6]. Gupta, Solanki, Koolwal, and Gehlot [7] hypothesized that healthcare providers, working with recipients and their caregivers, should investigate how the role of being caregivers plays on perception of the condition, treatment, and prognosis of

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recipients' afflictions. Likewise, Deniz and Inci [8] noted it is imperative the caregiver understands when his/her role changes from being a family member to being a caregiver.

The change in role may be difficult to identify because the transition to caregiver may be subtle in situations such as caring for patients with Alzheimer's (Matsumoto et al. 2007). However, in some instances, the caregiver may be able to identify the moment his/her role changes. For example, when a patient requires more supervision, the caregiver begins to neglect his/her own health because of intense focus on making the patient better or more comfortable [8]. It seems caregivers who continue to neglect their health and whose health begins to deteriorate may become easily frustrated, exhausted, and angry. A caregiver's deteriorating health, in addition to frustration and anger, will ultimately affect the quality of caregiving. Healthcare providers should attach more significance to a caregiver's health and the perceptions caregivers have of their roles if the patient is to benefit from the physical and psychological well-being of the caregiver. Caregivers with jobs outside the home whose health is deteriorating or who have negative perceptions of the burdens often decide to reduce work hours or stop work altogether to stay at home full time [1]. According to Colvez et al. (2013) a caregiver who reduces work hours to care for loved ones at home may begin to experience stressors motivated by factors related to financial difficulties, mental problems, social maladjustment, and physical issues. Society needs programs and interventions solely dedicated to reducing caregivers' perceived burdens and giving them alternative outlets to prevent excessive stressors. It would be good practice if healthcare providers take time in their busy schedules to frequently build working relationships with caregivers in order to establish the best methods of treatment for the family member with Alzheimer's disease as well the physical and mental health care of the caregiver [9]. Caregivers need support and understanding from healthcare providers and the general public in order to ensure that both the needs of the caregivers and the needs of patients with Alzheimer's are adequately met. There are more than 5 million Americans currently living with Alzheimer's disease. Many of them live in the community and depend on a family member for assistance. This research purposed to assess the perceived burden of care and quality of life among family caregivers of patients diagnosed with chronic illnesses (cardiac, cerebrovascular and Alzheimer diseases).

## Methods

### Design

The study was employed the descriptive cross-sectional survey.

### Settings

The study was conducted in the home care in Home health care Center in Jeddah. The home health care center in Jeddah provides comprehensive service to wide range of patients diagnosed with chronic illness such as cardiac, cerebrovascular and Alzheimer diseases.

### Sampling and Sample Size

The study utilized simple random sampling strategy. The reasons of applying this sampling technique are easy of administration, most economic and allows to collect large amount of data within short period of time. The study will use the level of confidence at 95%,  $p = 0.05$ , study power 80%, then the use of Cohen table shows that the required sample size is 390 and family caregivers 130 from each disease group. The inclusion criteria included family caregivers who provide

continuous care for at least six months, and they should provide care for relative diagnosed with these forms of chronic illness and they should agree to participate voluntary. Any family caregivers who have any form of mental illness were excluded.

### Outcome measures

The first part of the scale was related to sociodemographic data of the study participants such as age, gender, education level, marital status, income, relationship with ill relative, years of providing care. The Second part of the scale will be The ZBI includes 22 items recorded in a 0–4 Likert scale (total score range 0 to 88). They refer to problems arising in several domains: health and well-being, personal and social life and finances. As the ZBI assesses the feelings/thoughts of informal caregivers on the impact of the disease on their lives, it is considered to focus on the subjective component of burden of care. Higher scores on the ZBI mean higher burden [10]. The third part of the scale will assess quality of life by This scale was adopted from Ware Jr and Gandek [11] to assess the Quality of life level (QoL) of the participants. This scale has 36 questions divided into eight dimensions; Physical functioning (10 items), Role limitations due to physical health (4 items), Role limitations due to emotional problems (3 items), Energy/fatigue (4 items), Emotional well-being (5 items), Social functioning (2 items), General health (5 items), pain (2 items), Health change (1 items). Each item is rated on Likert scale ranged from 0 (no problem) to 5 (a lot of problems). The Cronbach alpha for the vitality subscale was 0.66 and between 0.77 and 0.90 for other subscales [12,13].

### Data analysis

Data were analyzed using the Statistical Program (SPSS) version 24. Before performing any statistical test, the researcher checked the achievement of statistical assumptions such as normality, linearity and homogeneity of variance. The study utilised descriptive and inferential tests to report the study results according to the variables nature. The study employed Pearson's Correlation Coefficient, independent sample t-test, and ANOVA analysis.

### Ethical Consideration

The study adhered with the ethical principles by the scientific research committee at directorate health affairs in Jeddah. In addition, the research obtained ethical approval from the ministry of health. The study participants delivered the information sheet as well as confidentiality was assured [14].

### Results

A total of 390 patients completed the survey questionnaire. The results showed that the majority of study participants aged 31 years or more. Moreover, more than half of the study participants were females. In terms of economic status, the majority of the participants had medium or low economic status. The results also indicated that two-third of the study participant's attained secondary education level or less. Moreover, one third of patients was married. Interestingly, almost of caregivers were parents who provided care for more than eight hours daily. Table 1 presents the sociodemographic characteristics of the study participants.

The results of Zarit burden interview score revealed that the family caregivers experience high level of burden of care as a result of providing continuous caregiving tasks, namely caregivers of patients diagnosed with mental illness. Looking at the results of subscale analysis indicated that the study participants demonstrated high impact of providing continuous caring activity as this evident from the scores

Characteristics	Frequency	Percentage
<b>Age</b>		
<30	37	9.50%
31-40	65	16.70%
41-50	89	22.85
>50	199	51.00%
<b>Gender</b>		
Male	191	48.90%
Female	199	52.10%
<b>Economic Status</b>		
Low	160	41%
Medium	143	36.70%
High	87	22.30%
<b>Education Level</b>		
Primary	126	32.30%
Intermediate	54	13.80%
Secondary	90	23%
Graduate and higher	120	30.80%
<b>Marital status</b>		
Single	127	32.60%
Married	133	34.10%
Others	130	33.30%
<b>Relationship with ill relative</b>		
Parent	322	82.50%
Offspring	38	9.70%
Others	30	7.60%
<b>Duration of providing care</b>		
<4 hours	34	8.70%
5-8 hours	97	24.80%
>8 hours	256	65.60%
<b>Relative diagnosis</b>		
Cardiacdisease	130	33.33%
Nervous system disorder	130	33.33%
Mental disorder	130	33.33%
<b>Patient information</b>		
<b>Age</b>		
<40 years	226	57.90%
40-55 years	94	24.10%
>55 years	70	17.90%
<b>Gender</b>		
Male	298	76.40%
Female	92	24.60%
<b>Marital status</b>		
Single	138	35.30%
Married	194	49.70%
Others	58	14.80%

**Table 1:** Sociodemographic Characteristics of Participants.

of consequences of caring. In addition, the nature of the disease renders the diagnosed patents fully relied on their family relatives in addressing their various needs (physical or physiological as well as psychological needs). This was reflected on the average of patient dependence subscale which is 14.24.

Additionally, it seems that the study participants blame themselves regarding ill relative disease as they feel guilt or criticize themselves. Furthermore, providing caregiving tasks for ill relative appeared to be demanding and negatively impact on the psychological status of the family caregivers. In the study, the average of psychological burden and emotional reaction to the ill relative was quite high which expresses the poor psychological and emotional problem of family caregivers. Consequently, this might have led the family caregivers to have a sense of embarrassment, anger or frustration of relative illness. This might be related to the poor understanding of illness nature, ill relative behavior and cultural factors. The findings of ZBI scale showed that family caregivers have trouble meeting the expected social roles. This is normally occurred when the family caregivers experience both role conflict as two roles have demands that are mutually exclusive alongside and role overload (when one does not have the resources to meet the demands of multiple roles). The average of role strain subscale is around 10.74 with standard deviation of 1.81. Table 2 summarizes the results of Zarit burden of care scale and its subscales. It is noted that family caregiver of patients diagnosed with mental illness reported statistically significant higher burden of care compared to family caregivers of patient diagnosed with nervous disorder or cardiac disease ( $p<0.05$ ).

The results showed that caring of ill relative diagnosed with Alzheimer disease have mainly produced consequences on family relatives. The results indicated that they showed that ill relative asks more frequently for external help and support (43%). Moreover, the majority of family caregivers appeared that caregiving tasks interferes with external family relationship as it restricts their socialization activity. This is evident from the study participants answers that 82% of family caregivers expressed interruption of caregiving task on their social networking and family connections. Moreover, the nature of relative illness seems that it disturbs the family privacy as 68% of family caregivers agreed that ill relative minimizes the family privacy. Notably, approximately half of the study participants agreed that family relative illness causes that family relative to lose their control over own life. In terms of the patient dependence subscale, the results showed that caregiving tasks made the family caregivers dedicated their time to provide the various needs of illness relatives. When the family caregivers were asked about their time and caregiving, two thirds of the study participants indicated that they have no time for themselves. This is evident with their answers regarding the questions of ill relative dependency on family caregivers in achievement his or her needs. Taken together, this had influenced with their social networking. Regarding the family caregivers' guilt or self-criticism revealed that family caregivers criticize themselves as they have no financial support to caring ill relative or feel exhausted not be able to keep providing constant care. Additionally, the family caregivers stated that they felt guilty or embarrassed as a result of their relative illness. The findings suggested that family caregivers experienced psychological and emotional burden. 70% of family caregivers perceived their health has suffered because of your involvement with your relative. Table 3 shows the family caregivers answers to the burden of care scale.

### Quality of life

Table 3 shows the scores of QOL in the four domains, overall QOL and general health. Comparing the four domains of the family caregivers, environment health domain which included living conditions and financial status was the highest with a mean score of

Subscale	Potential scores	Mental Health	Nervous disorder	Cardiac disorder	P
Consequences of Caregiving	(6-24)	18.65 (2.21)	13.65 (1.95)	10.87 (1.86)	0.034
Patient's Dependence	(4-16)	14.24 (1.68)	10.24 (0.98)	9.84 (1.02)	0.042
Exhaustion and Uncertainty	(2-8)	6.75 (1.34)	4.75 (0.95)	4.75 (0.93)	0.023
Guilt or Self-Criticism	(4-16)	14.62 (3.24)	12.62 (2.84)	10.37 (2.96)	0.038
Embarrassment/ Anger or Frustration	((4-16)	13.54 (2.87)	11.11 (2.17)	10.11 (1.78)	0.029
Psychological Burden and Emotional Reactions	(4-16)	14.68 (2.72)	11.22 (1.79)	10.12 (1.24)	0.041
Personal Strain	(1-4)	3.28 (0.89)	2.20 (0.75)	1.89 (0.58)	0.034
Role Strain	(3-12)	10.74 (1.81)	9.89 (1.56)	867 (0.89)	0.029

**Table 2:** Descriptive Statistics of Zarit Burden of Care Subscales.

54.45±16.54 while the psychological domain was the lowest with a mean score of 38.27±18.97. The family caregivers appeared to have negative perception of the physical pain, fatigue, sleep, daily activities, treatment dependence and work capacity. This is reflected from average of physical dimension as 43.80.

We have compared the differences in the average of burden of care subscales in relation to the sociodemographic characteristics. The results appeared that female's family caregivers were expressed higher negative consequences of caregiving tasks. It seems that the ill relative being more dependent when the family caregivers were females. Moreover, the female participants were more embarrassed from ill relative disease. The results also showed elder family caregivers reported significant perceived consequences of caregiving and had ill relative being more dependent compared with other age groups. These results also noticed among single family caregivers who reported more consequences of caring with greater dependence of ill relative. However, the married family caregivers expressed more guilt feeling with self-criticism compared to other groups. Education level of family caregivers played a role in perceiving consequence of caregiving. Expectedly, the employed family caregivers were reported significantly higher impact of caregiving consequences compared to unemployed family caregivers. Living with ill relative in the same house increased significantly the perception of caregiving tasks. Likewise, the length of caregiving and daily contact with ill relative influence in family caregiver's perception of caregiving tasks and patient dependence comparing to family caregivers who cared for ill relative less than five hours daily. Table 4 compared the burden of care subscales in relation to family caregivers' socio-demographic characteristics.

Unlike most other descriptive studies, this study went further to analyze the effect of caregiving burden on perceived quality of life. It also paves the way for future studies to examine specific values of all four domains to further identify and quantify the details of such impact. There was a good correlation between the burden as per ZBI and WHO-QoL-BREF scores in this study, which has been reported in previous studies.

### Physical burden

This study evaluated physical, social, financial and psychological burden, in family caregivers of AD patients. The level of caregiving burden experienced by a family caregiver depends on a variety of factors associated with both the caregiver and the care recipient such as demographic characteristics of caregivers like; sex, age, marital status, Female participants were more strongly associated with high burden than male ones the female caregiver's need for more help with

daily tasks was not so prominent as with males, The level of caregiving burden found in this study was similar across different previous studies and comparable to the level of burden previously documented among caregivers of patients with dementia and other chronic diseases suggesting that caregiving burden may not be disease-specific but may be a universal phenomenon of caring for older adults with chronic illnesses since the primary caregiver is more vulnerable to care burden than those who do not play a primary role in providing care (Greenberger & Litwin, 2003). Caregivers burden is referred to as the family caregivers' perceived level of distress, demands, and the pressure associated with caregiving roles, responsibilities and tasks. Previous studies have consistently documented caregiving burden and its effect on family caregivers for AD patient, including the psychological, physical, social, and financial and health consequences, since caregiving effects on family life in terms of the caregiver's time with their family and friends and efforts to balance it with other family responsibilities causes a greater level of burden for family caregivers. And if sacrifices had to be made to provide care to the AD patient, the level of burden was predictably higher because of the perception of sacrifice. Sacrifices can be associated with time, money, giving up luxury items, and the quality of relationships with others. The level of caregiver burden that is experienced by family caregiver can be affected by the culture to which they belong. Female family caregivers were expressed higher negative consequences of caregiving tasks. It seems that the AD patient being more dependent when the family caregivers were females. Moreover, the female participants were more embarrassed from AD patient.

In our study, it was found that family caregivers suffer from psychological distress at every stage of the process of providing care. The scores of QoL in the four domains, overall QoL and general health. Comparing the four domains of the family caregivers, psychological domain was the lowest with a psychological stability's mean score of 38.27±18.97 (95% CI) denoting that there is a linking relation with low QoL which is statistically significant among participant's scores and psychological domain. That is consistent with previous studies found that most of the family caregivers experienced anger, irritability, depression, anxiety symptoms. Another study conducted in Italy showed results that the family caregivers of patients affected by Alzheimer disease had high levels of anxiety and depression which highlights the presence of serious psychological problems. In our study female family caregivers were more likely to experience depression or psychological burden than are male caregivers who may be due to caregiver's relationship to the AD patient, living arrangements, and the amount of assistance provided to the female family caregiver. Female spouses in particular are prone to the ill effects of caregiving. With the stresses of caregiving continuing a finding suggests the

WHOQOL Domain	Mental Health	Nervous disorder	Cardiac disorder	P
Physical Domain	43.80 ± 28.45	38.45 ± 11.27	29.11 ± 11.24	0.034
Psychological Domain	38.27 ± 18.97	33.27 ± 11.64	29.11 ± 10.34	0.029
Social Domain	40.85 ± 28.67	34.45 ± 16.10	30.45 ± 11.10	0.031
Environment Domain	54.45 ± 16.54	46.45 ± 9.54	31.09 ± 9.01	0.029
Overall QOL	61.27 ± 9.11	58.38 ± 7.22	48.07 ± 7.68	0.019
General Health	63.22 ± 12.07	52.17 ± 10.19	47.67 ± 9.84	0.034

**Table 3:** The mean of WHOQoL-BREF among the family caregivers.

Characteristics	CoC	PD	EaU	GSC	EAF	PB	PS	RS
<b>Gender</b>								
Male	16.2	11.5	5.35	11.57	11.85	10.87	2.4	8.65
Female	20.7*	14.6*	7.3	15.34*	14.57*	14.35*	3.74	10.68
<b>Age</b>								
18-34 years	11.24	12.35	5.65	9.56	9.86	11.65	1.57	7.35
35-54 years	13.75	14.52	6.35	10.85	10.37	12.35	3.54	7.58
>55 years	16.85*	15.64*	7.3	11.65	11.87	14.37	3.57	8.68
<b>Marital status of caregiver</b>								
Single	22.37*	14.65*	6.35	11.27	12.24	13.57	2.57	8.65
Married	17.65	10.36	8.8	14.68*	14.65	14.87	3.64	10.89
<b>Education Qualification</b>								
Secondary or less	21.54*	14.65	7.65	13.89	13.85	14.52	3.52	8.68
Bachelor or higher	17.58	12.2	5.85	10.68	11.75	10.57	2.52	5.68
<b>Employment status</b>								
Unemployed	19.57	10.36	7.65	14.25	12.98	13.58	3.75	7.56
Employed	23.85*	12.35	6.49	11.35	10.67	11.37	2.57	4.85
<b>Living with care recipient in the same house</b>								
Yes								
No	22.35*	14.65*	14.56*	15.3	14.35	12.85	3.68	6.75
	16.57	10.28	8.85	10.37	12.3	9.6	2.35	4.35
<b>Hours of care</b>								
Less than 5 hours	17.65	10.85	10.25	14.35	13.57	10.57	2.92	4.82
More than 5 hours	20.98*	14.56	14.37	11.86	9.57*	13.57	3.75	6.27
<b>Length of care period</b>								
Less than 6 years	16.85	11.78	10.25	13.57	9.25	9.65	2.54	4.5
More than 6 years	23.54*	15.37*	15.38*	10.38	14.60*	13.25*	3.87	7.58

**Table 4:** Comparison of The Study Participants Responses of Burden of Care in relation to Demographic Characteristics.

importance of social support as it relates to lower QoL and depression in the caregivers.

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