

Depression Among Caregivers of Patients With Dementia

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Abstract

We aimed to assess depressive symptoms in caregivers of patients with dementia, taking into account variables such as severity of dementia, sex, age, and financial state of the patient. We recruited 222 caregivers of patients with dementia from King Abdulaziz Medical City, Saudi Alzheimer's Disease Association, and online, from February to June 2017, and employed the Patient Health Questionnaire to assess depression, and the Blessed Dementia Scale to assess severity of dementia. The prevalence of clinical depression among the caregivers was 14.9%. Minimal symptoms of depression were experienced by 96 caregivers (43.2%), moderate by 45 (20.3%), moderate-severe by 15 (6.8%), and severe by 8 (3.6%). Forty-six patients had mild dementia (22%), 73 had moderate (34.9%), and 90 had severe (43.1%). Caregivers of patients with dementia experience considerable burden and lower level of health-related quality of life and may be predisposed to developing clinical depression.

Keywords

depression, caregivers, dementia, Saudi Arabia, quality of life

Introduction

Dementia is a general term describing mental deterioration, mainly in cognitive function and memory, that may cause significant impairment in daily life activities. Alzheimer's disease and vascular dementia are the most common types of dementia.¹ These types of dementia are characterized by chronic degeneration of the central nervous system due to neuronal necrosis or malfunctioning.²

Dementia's psychological and behavioral signs and symptoms could be classified into 2 categories: (1) signs and symptoms that are assessed during interview with patients and caregivers such as anxiety, depressive mood, hallucinations, and delusions; and (2) signs and symptoms that are observed of patient behaviors including aggression, screaming, agitation, asking repetitive questions, culturally inappropriate behaviors, sexual disinhibition, and shadowing.³ In 2010, there were approximately 35.6 million patients with dementia worldwide, a number which is expected to double every 20 years to reach approximately 65.7 million patients with dementia by 2030 and 115.4 million by 2050.⁴ In Saudi Arabia, there are no official data regarding the number of patients with dementia, but it is estimated that there are at least 50 000 patients with Alzheimer's disease with dementia.⁵

The burden of dementia is not only limited to the patient. Other than the effect on the community and the economy of

the country, dementia also affects the family and the caregiver. One of the most daunting parts of caring for patients with dementia is agitation. There are many reasons that may induce agitation such as pain, discomfort, hunger, poor light, lack of sleep, and other reasons that would not cause agitation in healthy people. When the patient becomes agitated, he or she may become violent and behave in inappropriate and unusual ways that would never come from a loved one. The majority of caregivers of patients with dementia are family members. The occurrence of behavioral and psychological symptoms in patients with dementia and the cost of taking care of the patients appear to be very stressful to the caregiver, which may lead to depressive symptoms.^{6,7}

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A study conducted in Italy showed an increase of depressive symptoms among caregivers of patients with dementia (using the Zung Self-Rating Depression Scale) with high burdens level (using the Caregiver Burden Inventory).⁸ In Korea, a study showed a clear association between being a caregiver to a patient with dementia and increased risk of depression, especially in women and low-income families.⁹ Moreover, in Canada, female caregivers were found to be at higher risk of depressive symptoms than male caregivers.¹⁰ In the United States, a study compared depressive symptoms between caregivers of patients with dementia and other diseases, and it revealed a higher risk in caregivers of patients with dementia, mainly in elderly caregivers.¹¹

To our knowledge, there have been no similar studies discussing the association between caregivers of patients with dementia and depressive symptoms in Saudi Arabia. Our aim was to assess depressive symptoms in caregivers of patients with dementia, taking into consideration variables such as severity of dementia, sex, age, and the financial state of the patient. To improve satisfaction and quality of life of the caregiver, we assessed depressive symptoms to increase awareness within the health community to build a management plan that includes the caregivers along with the patients with dementia and to offer adequate assistance to the caregiver, particularly to groups that show a higher level of depressive symptoms.

Materials and Methods

Study Design and Setting

This was a cross-sectional study with data collected from King Abdulaziz Medical City Demented clinics, Saudi Alzheimer's Disease Association, and online. The data collection process took place from February 2017 through June 2017.

Participants and Sample Size

We targeted caregivers for patients with an already established diagnosis of dementia, and we excluded caregivers under 18 years old. In this study, we included both primary and secondary caregivers, which refers anyone who spend time caring for the patients by either helping them in their daily life activities or provided health-related caring, such as accompanying the patient in hospital appointments and administering medications. We implemented a convenience sampling technique, which we chose based on availability and willingness to contribute. The questionnaire was sent to 504 individuals, 222 of whom responded (response rate, 44%). The aim of the study was explained to each caregiver, with assurance of confidentiality, and we also obtained informed consent. The study's ethical approval was obtained from the King Abdullah International Medical Research Center (KAIMRC), Saudi Arabia.

Outcome Measures

The questionnaire was adopted from a previously validated questionnaire, the Patient Health Questionnaire "PHQ-9"¹¹ for depression and the Blessed Dementia Scale "BLS-D"¹² for dementia. The PHQ-9 includes questions on caregiver's demographics, symptoms, and depression score. The BLS-D assesses the severity of dementia symptoms for the patient, and how debilitating they are to the caregiver. We requested some additional information, including financial and residential responsibilities toward the patient.

The PHQ-9 is a self-administered multipurpose instrument, which can be used for screening, diagnosing, monitoring, and measuring the severity of depression. It has a sensitivity of 88% and a specificity of 88% for Major Depressive Disorder, which scores each of the 9 *Diagnostic and Statistical Manual of Mental Disorders* (4th ed.; *DSM-IV*) criteria from "0" (not at all) to "3" (nearly every day). PHQ-9 scores of 5, 10, 15, and 20 represented mild, moderate, moderately severe, and severe depression, respectively. According to the PHQ-9 for a diagnosis of major depressive disorder, 5 items or more should be checked with at least "more than half the days" and either item a. or b. should be checked with at least "more than half the days."

The severity of dementia was assessed using the BLS-D (Activities of Daily Living), which has a sensitivity of 90% and specificity of 85%, as a screening test for dementia. The BLS-D (Activities of Daily Living) is a questionnaire with 11 items that measure changes in performance of everyday activities, self-care habits (3 items), and changes in personality, memory, and ability to perform daily living activities (8 items). Ratings are based on information from relatives or friends and concern behavior over the preceding 6 months. BLS-D (Activities of Daily Living) Scores for each item: Total incapacity in an activity is rated 1 and partial, variable or intermittent incapacity is awarded a half-point, and self-care habits scores range from 0 if no change to 3 if total incapacity. Total scores refer to mild dementia (score: 0-5), moderate dementia (score: 6-11), and severe dementia (score: 12-17).

Statistical Analysis

Data were analyzed using IBM Statistical Package for the Social Sciences (SPSS, Chicago, Illinois) version 22. Categorical variables are presented as frequencies and percentages, and continuous variables as means and standard deviations. The association between depression and severity of dementia as well as the demographic variables was examined using the Pearson chi-square test. Forward stepwise binary logistic regression was used to determine the predictors of depression and to calculate the odds ratio (OR) and 95% confidence intervals (CIs). Depression was used as a dependent variable and the severity of dementia and demographic variables as independent variables. A result with a *P* value <.05 was considered statistically significant.

Table 1. Demographic Data of the Participants (N = 222).

Characteristics	Level	n	%
Sex	Male	89	40.1
	Female	133	59.9
Age group	20-40	103	46.4
	41-60	74	33.3
	>60	45	20.3
Relationship	Father/mother	134	60.4
	Other	88	39.6
Status	Married	126	56.8
	Single	96	43.2
Occupational status	Employee	157	70.7
	Unemployed	65	29.3
Time spent with the patient	>8 h a day	60	27.0
	≤8 h a day	89	40.1
	Not daily visitor	73	32.9
Patient's nurse	Yes	116	52.3
	No	106	47.7
Living with the patient	Yes	112	50.5
	No	32	14.4
Financially responsible for the patient	Yes	59	26.6
	No	163	73.4
Depression symptoms	No symptoms	58	26.1
	Minimal symptoms	96	43.2
	Moderate symptoms	45	20.3
	Moderate-severe symptoms	15	6.8
	Severe symptoms	8	3.6
Clinically depressed	Yes	33	14.9
	No	189	85.1

Results

A total of 222 caregivers of patients with dementia participated in the study and completed the questionnaire. More than half were women (60%, n = 133). Half of them were cohabitating with the patients (51%, n = 112), and 60% of them were sons or daughters of the patient with dementia (n = 134). The sociodemographic characteristics of the caregivers are presented in Table 1.

The prevalence of clinical depression (measured by the PHQ-9 and based on the *DSM-IV* diagnostic criteria for depression) among the caregivers of patients with dementia was 14.9% (n = 33). The mean PHQ-9 score of the caregivers was 7.98 ± 5.23 (maximum = 27). As shown in Table 1, minimal symptoms of depression were experienced by 96 caregivers (43.2%), moderate by 45 (20.3%), moderate-severe by 15 (6.8%), and severe by 8 (3.6%). The mean BLS-D score of patients with dementia was 9.73 ± 5.03 (maximum = 17). The caregivers were caring for 46 patients with mild dementia (22%), 73 with moderate (34.9%), and 90 with severe (43.1%).

Table 2 shows that there was no statistically significant association between patients' dementia level and their caregivers' depression scores ($P = .142$). The association of depression and the sociodemographic characteristics of the

Table 2. Association of Patients' Dementia Levels and Their Caregivers' Depression Rates.

Dementia level	Not depressed (n = 189)		Depressed (n = 33)		P value
	n	%	n	%	
Mild	42	91.3	4	8.7	.142
Moderate	63	86.3	10	13.7	
Severe	71	78.9	19	21.1	

Note. P values were calculated using the Pearson chi-square test.

caregivers is shown in Table 3. We found a statistically significant association between depression and the occupational status of the caregiver ($P = .009$). In addition, being responsible for the patient's financial obligations was significantly associated with depression ($P = .002$). No statistically significant association was found between depression and caregivers' sex ($P = .391$), their age ($P = .105$), or their marital status ($P = .387$). Depression was more prevalent among caregivers who were the sons or daughters of the patients with dementia, with borderline significant association ($P = .05$). No significant association was found between the caregivers who spent longer time with the patients ($P = .13$) or lived with them ($P = .206$) and depression.

Forward stepwise binary logistic regression was performed to identify the predictors of depression (the dependent variable) in the caregivers of patients with dementia, as shown in Table 4. We found that caregivers who were financially responsible for the patients with dementia were more likely to have depression (OR = 3.19, 95% CI: 1.47-6.49). Moreover, the risk of having depression was decreased in caregivers who were employed (OR = 0.01, 95% CI: 0.17-0.81).

Discussion

The present study strengthens our knowledge and understanding of factors associated with the increased risk of depression in the caregivers of patients with dementia. We analyzed 222 participants, who were caregivers of patients with dementia; the prevalence of depression was 14.9%, using the PHQ-9 as a screening tool. We chose the PHQ-9 because it is considered the best and most widely used instrument for screening depression in the primary care settings.^{13,14} Comparing our results with those derived from the general population, we found moderately increased depression scores in our study population. A study performed at King Abdulaziz Medical City in Riyadh, Saudi Arabia, showed that the depression rate in the general population was 12.6%.¹⁵ Moreover, a study conducted in Sharurah, Saudi Arabia, found the rate of depression to be 12%.¹⁶ Depression seems to be more prevalent in caregivers of patients with dementia, due to the burden and the difficulties that they face while caring for a patient with dementia.¹⁷

Table 3. Association Between Depression and the Caregivers' Characteristics.

Characteristics	Level	Not depressed (n = 189)		Depressed (n = 33)		P value
		n	%	n	%	
Sex	Male	78	87.6	11	12.4	.391
	Female	111	83.5	22	16.5	
Age group	20-40	93	90.3	10	9.7	.105
	41-60	61	82.4	13	17.6	
	>60	35	77.8	10	22.2	
Relationship	Father/ mother	109	81.3	25	18.7	.05
	Other	80	90.9	8	9.1	
Status	Married	105	83.3	21	16.7	.387
	Single	84	87.5	12	12.5	
Occupational status	Employee	140	89.2	17	10.8	.009*
	Unemployed	49	75.4	16	24.6	
Time spent with the patient	> 8 h a day	48	80	12	20	.13
	≤8 h a day	74	83.1	15	16.9	
	Not daily visitor	67	91.8	6	8.2	
Patient's nurse	Yes	103	88.8	13	11.2	.109
	No	86	81.1	20	18.9	
Living with the patient	Yes	92	82.1	20	17.9	.206
	No	97	88.2	13	11.8	
Financially responsible for the patient	Yes	43	72.9	16	27.1	.002*
	No	146	89.6	17	10.4	

Note. P values were calculated using the Pearson chi-square test.
*P < .05.

We found that 73.9% of caregivers had, to some degree, symptoms of depression: 43.2% minimal symptoms, 20.3% moderate symptoms, 6.8% moderate-severe, and 3.6% severe symptoms. Comparing this result with the study conducted in Riyadh, Saudi Arabia, concerning the general population, 49.9% experienced symptoms of depression of which 31% were mild, 13.4% moderate, 4.4% moderate-severe, and 1.0% severe.¹⁸ Comparing the general population with the caregivers of patients with dementia, the caregivers are at a higher risk for developing symptoms of depression in all categories, from minimal to severe. The reason could be the responsibilities they have toward the patients or the fact that one of their family members has an incurable chronic disease that is progressing. In the United States, a study using the PHQ-9 reported that 21.6% of caregivers had symptoms of depression, with the majority having mild symptoms.¹⁹ We propose that this significant difference with our study may be attributed to increased responsibility and stress imposed on the caregivers in Saudi culture.

As we could not locate similar studies conducted in Saudi Arabia, we compared our findings with those of other studies worldwide. A study conducted with nonprofessional caregivers in Galicia, Spain, found that 8.9% of caregivers met the criteria for major depressive episodes.²⁰ This discrepancy with

Table 4. Predicators of Depression in the Caregivers of Patients With Dementia.

Characteristics	Level	Depression		
		Significance	OR	95% CI
Financially responsible for the patient	Yes	.003*	3.188	(1.47-6.94)
	No ^a			
Occupational status	Employee	.013*	0.373	(0.17-0.81)
	Unemployed ^a			

Note. OR = odds ratio; CI = confidence interval.

^aReference group.

*P < .05.

our findings could be because they only measured depressive episodes but not clinical depression per se. A multicenter study in South America, with Hispanic/Latino women caregivers, found the depression percentage to be 25.8%.²¹ This is higher than our study, but this could be because they only included Hispanic/Latino women or because they used a different questionnaire. Comparing our study with a study performed in Catanzaro, Southern Italy, showing higher percentage of depression in Italian caregivers, this could be a result of cultural differences or differences in the instruments used.⁸

In this study, we examined whether there was a significant correlation between degree of severity of dementia and caregivers' depression and overall well-being. As seen in Table 2, our results showed no significant association with a P value of .142. This is similar to the results of previous studies, where they assessed the correlation between the severity of patients' disease and caregivers' well-being and revealed no statistically significant difference.²²⁻²⁴ Another study indicated that the insignificant correlation between the patient's disease severity and caregiver's degree of depression may be due to the fact that caregivers of patients with dementia are already at a lower level of health-related quality of life compared with the general population.²⁵ In our study, home nurses were available in 52.3% of caregivers' homes, but, interestingly, that did not result in a decrease in the degree of depression and burden among caregivers compared with those without home nurses.

Research regarding the difference of prevalence of depression among the sexes has shown that female caregivers exhibit more depressive symptoms than male caregivers.^{9,26} That was not the case in our study, where the prevalence of depression among male and female caregivers did not show any significant difference. This may be because, in our experience, most caregivers in Saudi Arabia are the sons and daughters of the patients, and it is considered a cultural duty for the whole family to be involved in the care of their relatives with dementia.²⁷ In addition, it is our understanding that in Saudi Arabia, the majority of financial providers are men, which may decrease the burden on female caregivers.

Another aspect that showed significance in the study conducted in Kumamoto University Hospital is older age, which did not significantly affect depression rates in our study; this could be because of cultural differences and the strong spiritual beliefs we have observed in the older population in the Saudi culture.²⁸ Moreover, similar to our study, time spent with the patient during the week did not significantly affect depression, and that may be because time spent with the patient is part of the duties caregivers feel they should provide.²⁹

There was a significant association in our study that caregivers are highly likely to develop depressive symptoms when they are financially responsible for the patient with dementia. This association may be explained by the increased financial demands and, thus, associated with higher burden imposed on the caregivers. Increases in financial obligations may increase the financial hardship of the caregivers and might affect their own lifestyle.³⁰ Unplanned changes in lifestyle may influence their quality of life and lead the caregivers to develop stress. Many studies have attempted to assess the changes in quality of life and their effect on caregivers.³¹ Better quality of life is strongly associated with the caregiver's good health and good financial status.³²⁻³⁴

Occupational status is one of the fundamental factors influencing caregivers' quality of life. We found, in our study, that depression is higher in caregivers who did not work compared with those who were employed. This may be due to the additional burden imposed on the individual who needs to work and take care of the patient with dementia. The association between occupational status and depression among caregivers has been reported in the literature to be a significant factor resulting in more distress and higher rates of depression.³⁵

Higher depression rates were found among caregivers who were the sons or daughters of the patients with dementia. We hypothesize that this may be due to the bond and strong relationship between the parents and their children; the children's feeling of responsibility toward their parents with dementia tends to be strong. This may elicit a sense of duty and maybe guilt and would increase the burden toward the related caregivers leading them to experience distress and depression.^{36,37}

To our knowledge, in Saudi culture, family support is strongly emphasized, and caregivers are expected to support their relatives with dementia, regardless of their financial status or any factors that may limit a caregiver to fully provide the needed support. Compared with the West, in Saudi Arabia, nursing homes are significantly fewer. It is our understanding based on our knowledge of Saudi society that the notion of patients with dementia residing in nursing homes is perceived as taboo in Saudi culture; therefore, caregivers are obliged to provide the full extent of the required support. This social pressure may increase the burden on the caregivers, exposing them to anxiety and depressive symptoms that may develop to clinical depression.

Our study had some limitations. First, the study was limited by its cross-sectional design; we did not perform a follow-up assessment regarding changes in depression status. Other than that, we did not control for factors that may be causative of depression, other than caregiver burden. Moreover, we did not assess the behavioral and psychological symptoms of dementia, which could contribute significantly to caregiver burden.

Conclusion

Our study showed that the caregivers of patients with dementia were at higher risk of developing depression compared with the general population. Moreover, the risk was markedly pronounced when the caregivers were financially responsible for the patient and when they were unemployed. An integrated management involving the caregiver should be encouraged to reduce the risk of developing depression in caregivers and to assist the caregivers in providing better care and service to their patients with dementia. Awareness of stress related to caregiving and education regarding dementia and its progression are key elements to helping caregivers adapt to their burden.

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