

Burden of Care among Dementia Caregivers Attending a Tertiary Care Clinic in Oman

Dr. Mandhar Al-Maqbali¹, Dr. Waddah Alalmaei Asiri², Dr. Hamed A-Sinawi³, Dr. Azza Al-Hinai⁴

¹Specialist Psychiatrist, Sohar hospital, Sohar, Sultanate of Oman

²Senior Registrar Psychiatrist, University of Najran Hospital, Najran, Kingdom of Saudi Arabia

³Sr. Consultant Psychiatrist, Behavioral Medicine, Sultan Qaboos University Hospital, Muscat, Sultanate of Oman

⁴Specialist Psychiatrist, Barka polyclinic, Barka, Sultanate of Oman

Abstract: **Background:** The term burden of care is defined as the subjective assessment of stress and anxiety which may result from the perception that external caregiving demands exceed available resources². The main domains of this burden are physical, emotional and financial burden. Several studies evidenced that caregivers are at increased risk of hypertension, dyslipidemia, and depression. **Objective:** to determine the degree of burden of care among caregivers of people with dementia attending the Memory Clinic, Sultan Qaboos University Hospital, Oman **Methods:** This is a cross-sectional study conducted in Sultan Qaboos University Hospital in the period from May 2014 to March 2015. All dementia caregivers accompanying their relative to the memory clinic at Sultan Qaboos University Hospital were invited to participate in this study. The diagnosis of dementia was based on DSM 5 criteria, and the severity was rated according to the Global Deterioration Scale for Assessment of Primary Degenerative Dementia and Clinical Dementia Rating. The level of dependency was measured using the Katz Index of Independence in Activities of Daily Living (ADL) and Lawton Instrumental Activities of Daily Living (IADL) Scale. For the caregivers, Zarit Burden Interview (ZBI) was used to determine the burden of care. **Results:** 50 patients with dementia and their primary caregivers were included in the study. 90% of caregivers were adult children who are supported by other relatives. As quantified by ZBI, 70% of caregivers demonstrated a high degree of burden. Factors such as patient's age, duration, and severity of dementia, the level of dependency and female gender of the caregiver were associated with higher burden. **Conclusion:** The burden is common among dementia caregivers and several factors interplay to influence the perceived stress. As increased burden was evidenced to be associated with higher incidence of mental disorders, screening, and early intervention will impact positively on the caregiver as well as the patient.

Keywords: Dementia, caregiver, burden, Oman

Declaration of interest: None

1. Introduction

Providing care to patients with dementia is associated with significant risk to the caregivers' health and well-being¹. The term burden of care is defined as the subjective assessment of stress and anxiety which may result from the perception that external care giving demands exceed available resources². The main domains of this burden are physical, emotional and financial burden. Several studies evidenced that caregivers are at increased risk of hypertension, dyslipidemia, and depression^{3,4,5}. Various factors were proposed to influence the overall perception of burden including female gender, advanced age of the caregiver, low income and decreased quality of life⁶⁻¹¹. Moreover, presence of medical comorbidities and behavioral disturbance in the care-recipient are known factors to worsen the perceived burden⁶⁻¹¹. The outcome of this burden will impact negatively on the patient and his caregiver. Dementia is an acquired decline in global cognitive functions and the primary cause of disability among the elderly¹¹. The risk of developing dementia was estimated to be 5% of people aged 65-years old and its prevalence increases with age¹². Behavioral disturbances including agitation, dysphoria and aberrant motor behaviors present in up to 88% of patients¹³. The patient becomes increasingly dependent on activities of daily living demand more assistance and care with progression of the dementia

The World Health Organization has estimated that by 2025, the population of people aged 60 and over will be approximately 1.2 billion, increasing by 223% from the population in 1970¹⁴. In Oman, the national center of Statistics estimated that the percentage of people aged 60 and above to be 5.4% in 2010. This figure is projected to reach 9.2 in 2025, 20.4% in 2050. (National census, Sultanate of Oman 2014).

In Oman, the culture is highly based on the Islamic regulations which recommend the care for elderly parent. Islam contains principles and precepts that create family obligations to afford physical, mental, and emotional comfort to the elderly¹⁵⁻¹⁶. For instance, the opportunity to attend the needs of parents in their later life is viewed as a gift from the religious perspective¹⁶

At present, there are no published studies in Oman about the burden of care experienced by caregivers of people with dementia. This study aimed to assess the prevalence and predictors of burden among dementia caregivers attending a tertiary care hospital in Oman.

2. Methods

Study design and sampling:

This is a cross-sectional study conducted in Sultan Qaboos

university hospital in the period from May 2014 to March 2015. All dementia caregivers accompanying their relatives to the memory clinic at Sultan Qaboos University Hospital were invited to participate in this study. Those who could not wait to fill the questionnaire or were not accompanied by the primary caregiver and those who refused to give consent were excluded from the study. The Ethics Committee at College of Medicine and Health Sciences, at Sultan Qaboos University, granted ethical approval. All caregivers gave their written informed consent before enrollment.

Patients' demographic characteristic, duration of dementia and presence of co-morbidities were documented. The diagnosis of dementia was based on DSM 5 criteria for neurocognitive disorder. Global deterioration scale (GDS) was used to assess the degree of the cognitive decline. GDS was developed primarily to give an overview of the stage of cognitive function for patients with primary degenerative dementia¹⁷. On the other hand, clinical dementia rating (CDR) scale was implemented to quantify the severity of dementia and its associated cognitive and functional impairment. CDR is a semi-structured interview with high inter-rater reliability in assessing the cognitive and functional performance of patients with dementia¹⁸⁻¹⁹.

The patients' cognitive impairment at the time of the study was assessed using Folstein mini-mental examination (MMSE). Levels of basic and instrumental dependency were measured by Katz index of independence in activities of daily living (ADL) and Lawton Instrumental Activities of daily living (IADL) respectively. Katz ADL and IADL are validated numerical tools to assess the patients' functions and the level of dependence on the caregivers²⁰⁻²¹. For Katz ADL, total points of zero indicate high dependency while scoring total points of six signifies independence.

Zarit Burden Interview (ZBI) was used to measure subjective burden among caregivers. ZBI is the most widely used instrument for assessing the burden experienced by the caregivers of patients with dementia²². It is a 22-item self-report inventory that evaluates the caregiver's health condition, psychological well-being, finances and social life. Each question is scored on 5-point scale ranging from "never" to "nearly always" present with total score of 88 (high burden)²³.

There is no census regarding the cut-off point at which the caregiver will require further assessment and intervention. However, Schreiner and his colleagues concluded that a cut-off score of 24 is useful in identifying caregivers at risk of depression and warrant further investigations²⁴. Therefore, in this study a cut-off point of 24 and above was considered as high burden.

Data Collection

The collected data for the patients include age, gender, duration of onset of symptoms of dementia and presence of physical comorbidities. For the caregivers, the collected data include age, gender, educational level and relationship to the patient.

Data analysis:

Data were inputted using Epi Data Software (version 3.1). Then the data was exported to SPSS for Windows (version 20) for analysis. The correlation between ZBI score and other possible factors was calculated using Chi-Square test.

3. Results

A total of 50 patients with dementia and their primary caregivers were included in the study, (F: 58% M: 42%). The average age of patients was 72 years and more than 50% had moderate to severe dementia with significant impairment based on GDS and CDR scales. The mean time between onsets of symptoms to presentation to old-age clinic is three years. Most patients (78 %) had other medical disorder before diagnosis of dementia. Using Katz ADLs, 18% of patients were very dependent on the caregivers compared to 32% who lives independently. The average score for MMSE was 8 out of 30.

Table 1: The mean of activities of daily livings score, duration of dementia and MMSE and severity of dementia

	Mean	Std. Deviation
Katz ADL	3.16	2.385
Lawton Instrumental ADL	0.66	1.222
MMSE	8.12	5.882
Global clinical dementia rating scale	5.42	1.052
Clinical Dementia Rating Scale	2.22	1.036

Table 2: The mean age of the caregivers, the gender and the mean of Zarit Burden Score

Caregivers' age (mean)	40 years
Sex of the caregivers	
-Female	54%
-Male	46%
ZBI score (mean)	34

Table (1) shows the means for Katz ADL, Lawton IDL, duration of dementia, GDS and CDR. (ADL: Activity of daily living, MMSE: Mini-mental state examination GDS: global dementia rating scale, CDR: Clinical Dementia Rating Scale).

Most of the caregivers were adult children (90%) who are supported by other family members. Female caregivers constitute 54% of all caregivers Table (2). The average age of the caregivers was 40 years and majority of them (70%) reported high burden of care. The mean ZBI score for all caregivers was 34 (Table 2).

There was significant positive association (p<0.05) between severity of dementia and increased care giving burden. Among the caregivers, 63 % of those who provide care for patients with severe impairment reported high burden. Mean while, only 3% of caregivers for patient with mild impairment reported high burden Table (3)

Table 3: Relationship between Global Dementia Scale and Zarit Burden Interview score

Global clinical dementia rating scale	No Burden	High Burden	Total
mild cognitive impairment	4	0	4
Mild dementia	1	4	5
Moderate dementia	4	7	11
Moderately severe dementia	5	21	26
Severe dementia	1	3	4
Total	15	35	50

ZBI : Zarit Burden Interview

Table (3) illustrates the association between the severity of dementia and high burden of care using Chi-Square ($p < 0.05$) (GDS: Global Deterioration Scale, ZBI: Zarit Burden Interview).

Katz ADLs total points scores were categorized as independent, dependent and very dependent. The primary caregivers of very dependent patients – Katz ADL score below 2- experience more burden than other caregivers. This relationship between level of dependency and ZBI score is statistically significant ($p < 0.05$). Table (4)

Table 4: Relationship between levels of dependency and Zarit Burden Interview score

Levels of dependency	No Burden	High Burden	Total
Very Dependent	4	20	24
Dependent	1	6	7
Independent	10	9	19
Total	15	35	50

Table (4) illustrates the relationship between levels of dependency and ZBI score. Levels of dependency reflects the Katz ADLs total points score. Very dependent (Katz ADL ≤ 2 , dependent [3 – 4] and independent ≥ 5) (ADL : Activity of Daily Livings).

Also, caregivers for the patients aged between 60-79 years reported more burden than caregivers of the other age groups. Moreover, increased duration of dementia was found to be associated with increased burden of care. MMSE score was negatively correlated with ZBI score. However, these differences were not statistically significant.

4. Discussion

This is the first study from Oman that examines the burden of providing care to patients with dementia. It demonstrates that care giving is associated with high levels of burden. Factors including severity of dementia, patient's age and duration since diagnosis were associated with higher degree of burden. These findings are consistent with other studies in literature²⁵⁻²⁷.

High degree of burden reported in this study can be explained by several factors. The majority of patients recruited for the study had moderate to severe dementia which is linked to higher degree of burden²⁶. Furthermore, low score of MMSE and high level of dependency could culminate in higher burden. Finally, most of the caregivers involved in this study were females who experience a higher degree of burden than male caregivers³.

Caregivers-related factors included younger age, higher

education and higher cost of home care. These specific factors are best explained by the social, cultural and financial situation of Korea, where this study was conducted²⁸.

Furthermore, a greater sense of responsibility to care for elderly family members and a reluctance to discuss family problems are more common among Asian cultures. This may lead to less social and emotional support to the caregivers, resulting in a higher burden²⁹.

In Oman and other Islamic countries, the culture is mostly shaped by the Islamic percepts and principles which recommend providing optimal care for elderly family members. On the other hands, caregiving is viewed as a gift as it is linked to the good deeds leading to paradise. However, specific studies are required to examine the burden of care among caregiver of this cultural background.

5. Limitations

This study included 50 patients and their primary caregivers. This relatively small sample size had limited the statistical significance between burden of care and other variables like dementia duration and patients' age. Also, patients recruited for this study were attending tertiary health care hospital. Those patients are more likely to have advanced stage of dementia and possibly more behavioral disturbance, resulting in a higher burden of care. Future studies in this regard may consider comparing caregivers with high burden of care with those experiencing no burden in an extensive assessment. Moreover, the tools employed in the study were not validated among Omani patients and their primary caregivers.

6. Conclusion

The burden of care is common among primary caregivers of patients with dementia. This burden is the result of interplay between several factors related to the patients and her caregiver. Several studies have shown that the caregiver is at risk of physical and mental problems as a result of caregiver burden. Therefore, screening for burden and regular physical and mental assessment are highly recommended for the caregivers to prevent the adverse effects of burden of care. Also, health-care providers should emphasize on early interventions and promote the mental and physical health of the caregivers.

7. Acknowledgment

The authors would like to thank all the caregivers who participated in this study

References

- [1] Todd J. Richardson & Soo J. Lee & Marla Berg-Weger & George T. Grossberg. Caregiver Health: Health of Caregivers of Alzheimer's and Other Dementia Patients. *Curr Psychiatry Rep* (2013) 15:367.
- [2] Werner S, Auslander GK, Shoval N, et al. Caregiving burden and out-of-home mobility of cognitively impaired care-recipients based on GPS tracking. *Int*

- Psychogeriatr. 2012;24(11):1836–45.
- [3] Roepke SK, Mausbach BT, Patterson TL, et al. Effects of Alzheimer caregiving on allostatic load. *J Health Psychol.* 2011;16 (1):58–69.
- [4] Vitaliano PP, Zhang J, Scanlan JM. Is caregiving hazardous to one's physical health? A meta-analysis. *Psychol Bull.* 2003;129(6):946–72.
- [5] Joling KJ, van Hout HPJ, Schellevis FG, et al. Incidence of depression and anxiety in the spouses of patients with dementia: a naturalistic cohort study of recorded morbidity with a 6-year follow-up. *Am J Geriatr Psychiatry.* 2010;18(2):146–53.
- [6] Werner P, Mittelman MS, Goldstein D, Heinik J. Family stigma and caregiver burden in Alzheimer's disease. *Gerontologist.* 2012;52(1):89–97.
- [7] Quinn C, Clare L, McGuinness T, Woods RT. The impact of relationships, motivations, and meanings on dementia caregiving outcomes. *Int Psychogeriatr.* 2012;24(11):1816–26.
- [8] Shahly V, Chatterji S, Gruber MJ, et al. Cross-national differences in the prevalence and correlates of burden among older family caregivers in the World Health Organization World Mental Health (WMH) Surveys. *Psychol Med.* 2013;43(4):865–79.
- [9] Lautenschlager NT, Kurz AF, Loi S, Cramer B. Personality of mental health caregivers. *Curr Opin Psychiatry.* 2013;26(1):97–101.
- [10] Wolfs CA, Kessels A, Severens JL, et al. Predictive factors for the objective burden of informal care in people with dementia: a systematic review. *Alzheimer Dis Assoc Disord.* 2012;26(3):197–204.
- [11] Marvardi, Martina, et al. "The Caregiver Burden Inventory in evaluating the burden of caregivers of elderly demented patients: results from a multicenter study." *Aging clinical and experimental research* 17.1 (2005): 46-53.
- [12] Kalaria, Raj N., et al. "Alzheimer's disease and vascular dementia in developing countries: prevalence, management, and risk factors." *The Lancet Neurology* 7.9 (2008): 812-826.
- [13] Mega MS, Cummings JL, Fiorello T, et al.: The spectrum of behavioral changes in Alzheimer's disease. *Neurology* 1996, 46:130–135.
- [14] Alzheimer's Disease International. *World Alzheimer Report 2015: The global impact of dementia*, London: Alzheimer's Disease International; 2015
- [15] Tahir Mahmood, *Law and the Elderly in the Islamic Tradition—Classical Precepts and Modern Legislation*, IX ISLAMIC & COMP. L. Q. 33, 33 (1989).
- [16] Surat Al.Isra'a. Ayat 24 -25. *The Holy Quran*
- [17] Reisberg, B., Ferris, S.H., de Leon, M.J., and Crook, T. The global deterioration scale for assessment of primary degenerative dementia. *American Journal of Psychiatry*, 1982, 139: 1136-1139.
- [18] Morris, J.C. The Clinical Dementia Rating (CDR): Current vision and scoring rules *Neurology*, 1993; 43:2412-2414
- [19] Rockwood, Kenneth, et al. "Interrater reliability of the Clinical Dementia Rating in a multicenter trial." *Journal of the American Geriatrics Society* 48.5 (2000): 558-559.
- [20] Katz, Sidney. "Assessing self-maintenance: activities of daily living, mobility, and instrumental activities of daily living." *Journal of the American Geriatrics Society* 31.12 (1983): 721-727.
- [21] Lawton, M.P., and Brody, E.M. (1969). Assessment of older people: Self-maintaining and instrumental activities of daily living. *The Gerontologist*, 9, 179-186.
- [22] Hébert, Réjean, Gina Bravo, and Michel Préville. "Reliability, validity and reference values of the Zarit Burden Interview for assessing informal caregivers of community-dwelling older persons with dementia." *Canadian Journal on Aging/La Revue canadienne du vieillissement* 19.04 (2000): 494-507.
- [23] Zarit SH, Orr NK, Zarit JM. *The hidden victims of Alzheimer's disease; families under stress.* New York: New York University Press; 1985.
- [24] Schreiner, Andrea S., et al. "Assessing family caregiver's mental health using a statistically derived cut-off score for the Zarit Burden Interview." *Aging and Mental Health* 10.2 (2006): 107-111.
- [25] Freyne, Aileen, et al. "Burden in carers of dementia patients: higher levels in carers of younger sufferers." *International journal of geriatric psychiatry* 14.9 (1999): 784-788.
- [26] Yuen Oi Choong, Tanya-Marie, et al. "dementia caregiver burden among asians: influence of disease severity and age of onset." *Alzheimer's & Dementia: The Journal of the Alzheimer's Association* 10.4 (2014): P605-P606.
- [27] G. Karlikaya, G. Yukse, F. Varlibas, H. Tireli: *Caregiver Burden In Dementia: A Study In The Turkish Population.* *The Internet Journal of Neurology.* 2005 Volume 4 Number 2. DOI: 10.5580/2587
- [28] Kim, J. M., Shin, I. S., Jeong, S. J., Gormley, N., & Yoon, Y. S. (2002). Predictors of institutionalization in patients with dementia in Korea. *International Journal of Geriatric Psychiatry*, 17, 101–106.
- [29] Etters, Lynn, Debbie Goodall, and Barbara E. Harrison. "Caregiver burden among dementia patient caregivers: a review of the literature." *Journal of the American Academy of Nurse Practitioners* 2 (2008): 423-428.

Author Profile

Dr. Mundher Al Maqbali, Specialist Psychiatrist, Al Massara Hospital, Muscat, Sultanate of Oman. Email: omanlion84@yahoo.com