

Caregiver Stress between Carers of Dementia Patients

Nora A. Mossad^{1,2}, Sarah A. Hamza¹, Hoda M. F. Wahba¹, Heba Y. Youssif¹ and Mohammad F. Tolba^{1,2}

¹Department of Geriatrics and Gerontology, Faculty of Medicine, Ain Shams University

²Geriatric Palliative Care Unit, Ain Shams University Hospitals

ABSTRACT

Introduction: Care-giving of dementia patients can be stressful, especially when a patient has significant behavioral and psychological symptoms of dementia (BPSD), causing high levels of stress and burnout.

Objective: To study prevalence and risk factors of caregiver stress between caregivers of dementia patients.

Methods: Ninety-seven (97) elderly subjects were collected from geriatrics memory clinic and ward at Geriatrics Hospital, ASUH located at Cairo, Egypt. Dementia was diagnosed by Minimental state exam (MMSE). Patients' data were obtained. Relevant clinical events, including frequency of BPSD episodes in the last 2 months before enrollment in the study, were recorded. Caregiver stress among carers was checked by Zarit Burden Interview (ZBI-A).

Results: Our results showed high prevalence of caregiver stress among studied caregivers; with 27% reporting mild to moderate burden and 68% reporting high burden. Among studied parameters, ZBI-A score was positively correlated with patient age, caregiver age, frequency of delirium episodes, frequency of BPSD episodes, and frequency of home visits emergency room (ER) visits, and hospital admissions. In contrast, ZBI-A score was negatively correlated with MMSE score.

Conclusion: Caregiver stress is a significant concern for individuals caring elderly with cognitive impairment; and it is predisposed by a complex interaction of patient aspects, disease factors, and caregiver characteristics. The severity of the disease, the frequency of BPSD, and the carer's own health all play crucial roles in determining the level of stress the caregiver faces.

Keywords: Dementia, Caregiver stress, Caregiving burden, Elderly.

Introduction

Dementia is the seventh major causes of death in the elderly population; it not only affects individuals but also has profound impacts on families, healthcare systems, and societies [1]. Total care of dementia in the entire Arabic countries approaches 13.9 billion dollars [2].

Dementia is strongly age-associated, and the prevalence increases significantly between older adults, especially elderly aged 80 and above. Research has shown that individuals over 80 are at a much higher risk of dementia, particularly Alzheimer's disease. Also, its incidence was more between illiterate sets than between educated sets [3]. Dementia cases in Egypt during 2019 were 305675 and are expected to reach 1530167 in 2050 [4].

Caregivers are anticipated to have significant stress when they do not have enough health education [5]. Taking care of a loved one complaining of cognitive troubles is one of the most challenging caregiving situations, marked by chronic stress, emotional strain, and physical exhaustion. The nature of dementia, with its progressive deterioration and gradual loss of cognitive and functional abilities, makes caregiving particularly stressful and demanding. [6].

Caregivers with pre-existing health conditions face multiple challenges in managing both their own health and the needs of the elderly they are caring for. Without proper support, this dual burden causes worsening health for the carer and an increased risk of caregiver burnout [7].

As elderly demented subjects grow—driven largely by aging populations—so too does the pressure on family caregiver and informal caregivers to offer long-standing

care. This burden may have serious implications for caregivers' mental, emotional, and physical health, often leading to stress, depression, and other health problems [8].

Up to now, no cure for most common dementias exist [9]. But, many plans have been made to apply valuable care models for dementia. Dealing with bothering behaviors, teaching of carers, and adjustment approaches help improving patient/carer life [10].

Efforts to design tools to assess burden of care were initiated starting more than 40 years ago [11]. Tools, at that time, were not self-performed forms. That was modified by Zarit et al. [12]. Their tool was widely utilized since then, being most famous in this field of studying care burden [13].

Caring of elderly with troubling behaviors at home or in facilities needs approaching both the individual and the carer, including determining which behaviors are present, preparing intervention needed, and monitoring for success [14].

The aim of current work is to elucidate prevalence of caregiver stress in carers of dementia patients; and to explore the risk factors associated with caregiver stress in this particular category.

Methods

Current study was a cross-sectional study of elderly patients, aged 60 years and above, of both sexes, and their caregivers. Cases were clinically confirmed to have dementia. They were collected from the inpatient ward and outpatient clinics of the Geriatrics Hospital, one of the Ain Shams University Hospitals (ASUH), located at Cairo.

The study were revised and accepted by the ethical committee- Faculty of Medicine, Ain Shams University. PASS11 program was utilized for sample size determination; with 10% margin of error and at 95% confidence level. A sample size of 97 participants was requested.

We screened all attending patients for eligibility criteria. Each eligible patient who (and/or his/her caregiver) was willing to share in the study was included; until a sample size of 97 patients and their caregivers was completed. For participating caregivers, a minimum period of caregiving was required to be at least 2 months.

We excluded patients with: critical illness, any problem interfered with initial assessment (e.g., delirium), and patients who couldn't be interviewed face to face at the first clinic visit.

Each patient underwent:

- (1) Comprehensive Geriatric Assessment (CGA):
 - Complete demographic data (e.g. age, gender) and detailed past medical history and physical examination.
 - MMSE [15] for evaluation of cognition [16]. All patients scored less than the age/education-specific cutoff score for dementia diagnosis.
- (2) Detailed inquiry as regards the following events in the last 2 months before enrollment: episodes of delirium, BPSD (anxiety, irritability, delusions, hallucinations, agitation/aggression, disinhibition, abnormal motor activity/wandering, or night-time behavioral disturbances), the frequency of clinic visits, home visits, emergency room (ER) visits, and hospital admissions.

For caregivers:

- Socio-demographics were obtained regards to education, age, type of caregiver.
- Assessment of caregiver stress using Arabic Zarit Burden Interview (ZBI-A) [17]. It is a 12-item useful screening tool (0 to 4 points per item, giving a total score of 0-48). Total scoring is classified as follows: 0-10: no to mild burden, 11-20: mild to moderate burden and >20: high burden.

Ethical Considerations:

The methodology of the study received approval from the ethical committee-Faculty of Medicine, Ain Shams University (Approval Code: MD 19/2021). No one has the right to read patient's medical information except the researchers.

Statistical Analysis:

Convenient statistical methods were used to analyze the data. Descriptive statistics for quantitative data were mean \pm SD, as well as frequency and percentages for qualitative data. Comparisons were analyzed by appropriate statistical tools. The data were collected, reviewed, coded, and tabulated using SPSS 23.0 (2015). A P-value < 0.05 was deemed significant.

Results:

Table (1a): study patients were predominantly males (62.8%), mean age was 74 years, 45% were illiterate. All dementia stages were represented. Mean MMSE score was 16.7 points. Regards caregivers, as shown in table (1b), 64.9% were females, they had a mean age of 37 years, most of them were educated (secondary/university education). Of note, 86.6% were family caregivers.

Table (2a) shows high prevalence of caregiver stress among studied caregivers; with 27.8% reporting mild to moderate level of burden and 68% reporting high burden. As regards the individual questions, as shown in table (2b), caregivers reported variable responses. The three most prevalent “Nearly always” responses were to the eighth question (social life suffering), the eleventh question (feeling he/she should be doing more for his/her relative), and the twelfth question (feeling he/she could do better in patient care).

Univariate analysis showed that ZBI-A score was positively correlated with patient age, frequency of delirium episodes, frequency of BPSD episodes, and frequency of home consultations, ER visits, and hospital admissions in the last 2 months. It was also positively correlated with caregiver age. In contrast, ZBI-A score was negatively correlated with MMSE score. This is illustrated in table (3).

Table (4) shows that more advanced dementia stage was associated with higher caregiver stress scores.

Regression analysis model for risk factors associated with caregiver stress is shown in table (5). Lower MMSE score, increased frequency of BPSD episodes in the last 2 months and older caregiver age were independently associated with caregiver stress as measured by Zarit Burden Interview-Arabic.

Discussion:

Caring for a demented subject can lead to significant burden and stress, especially with disease progression. In our study, results showed that “mild to moderate” burden occurred in 27.8% of carers and “high burden” in additional 68% of carers; giving a total prevalence of 95.8%. These figures

represent frequent caregiver stress in the carers of studied patients.

Globally, more than 80% of caregivers of Alzheimer disease patients stated that they commonly develop high level of stress; and around 50% reported that they suffered from depression [18].

Previous studies in caregivers of the elderly individuals reported variable figures for the prevalence of caregiver stress and burden. For instance, Nasreen and colleagues studied the caregiver burden of relatives of dementia subjects living in Malaysia. In their work, prevalence of caregiver’s burden approached 70%. Depression was reported in 32.2% of caregivers. Family caregivers who perceived support (e.g., social or family support) experienced fewer burdens and less depression [19].

In another recent study regards older patients in the emergency room, caregiver burden affected around 40% of the caregivers who reported a high burden [20].

Some caregivers are more susceptible to suffer from caregiving burden in comparison to others. Current study illustrates that ZBI-A score was positively correlated with patient age, frequency of delirium episodes, frequency of BPSD episodes, and frequency of home consultations, ER visits, and hospital admissions in the last 2 months before inclusion. It also had a positive correlation with caregiver age.

Increased caregiver stress scores were associated with more advanced dementia stage in the patient (i.e., carers of patients with severe dementia had higher mean ZBI-A score). ZBI-A of studied carers had a negative correlation with MMSE scores of studied patients.

Regression analysis was performed to explore the risk factors related to caregiver stress. Lower MMSE score, more frequent

BPSD episodes in the last 2 months and older caregiver age were independently associated with caregiver stress; as measured by ZBI-A.

In the work done by Zaalberg et al., caregivers suffering from high burden, compared to those experienced low burden, were frequently caring of patients with dementia [20].

Previous studies reported on different factors possibly associated with caregiver stress. Among these factors, both the frequency of BPSD and the age of carers were reported to contribute to caregiver stress. The ZBI effectively highlights these relationships, emphasizing the need for targeted support for older caregivers dealing with patients with frequent BPSD episodes [19].

Dementia-related psychotic features, which include hallucinations and delusions, contribute to caregiver burden and may precipitate institutionalization [21].

Similar to our findings, caregivers with more advanced age were found to experience more burden related to caregiving, compared to their younger counterparts [22]. Various studies had found that carer's age influenced his/her burden; advanced carer's age led to increased level of burden [23].

Dementia stage is another important factor. We found that carers of patients with severe dementia had higher mean ZBI-A score. This finding was expected, as agitation occurs more in patients with later stages of dementia [24]. Similarly, psychotic features are prevalent in later stages of the disease [25].

Shim and colleagues, in their 1-year follow-up study, evaluated the factors related to caregiver burden in dementia. They

concluded that caregiver burden, and subsequent neglect, can negatively affect the outcome/progression of dementia in the patient, and increases the likelihood that the patient will need care services and facilities [26]. In our study, this was demonstrated by the finding of higher frequency of delirium, BPSD, and the number of domiciliary consultations, visiting the ER, and admissions in patients whose caregivers had higher caregiver stress scores.

The educational level of the caregiver was found to have a negative correlation with the burden; one explanation is that the higher educational level led to high income which would alleviate the financial burden, as demonstrated by a study of caregivers of people suffering from dementia [27]. Another explanation is that the high educational level of caregiver could indicate more accessibility to knowledge about dealing with burden/stress [28]. In our cohort, no significant association was found between educational level and caregiver stress, as we included a few number of illiterate caregivers.

Applying psycho-educational interventions in this population can significantly benefit caregivers. These interventions can help caregivers better understand the nature/course of the disease, who to deal with dementia symptoms, and when to ask for support. All of these can improve both patient and caregiver's outcomes [19].

Conclusion:

Caregiver stress is a significant concern for individuals caring for dementia patients, and it is affected by a complex interaction of patient factors, disease factors, and caregiver characteristics. The disease severity, the presence of BPSD, and carer's own health all play crucial roles in determining the degree of stress perceived by the caregiver.

Addressing these factors through education, respite care, psychological support, and self-care can help reduce caregiver burden and enhance patient's care.

Conflicts of interest: None.

Study limitations: Inclusion of caregivers having different living situations, educational levels, residence areas, and social supports would help to study more risk factors related to caregivers that may be associated with caregiver stress.

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Table (1): Baseline data

Table (1a): Patients' characteristics

| N=97 | | N | % |
|-----------------------------------|---------------|--------------------|-------|
| Gender | Male | 61 | 62.89 |
| | Female | 36 | 37.11 |
| Education | Illiterate | 44 | 45.36 |
| | Primary | 8 | 8.25 |
| | Preparatory | 10 | 10.31 |
| | Secondary | 23 | 23.71 |
| | University | 12 | 12.37 |
| Marital state | Widow | 48 | 49.48 |
| | Married | 46 | 47.42 |
| | Divorced | 3 | 3.09 |
| Smoking | Current | 19 | 19.59 |
| | Ex-Smoker | 28 | 28.87 |
| | Non-Smoker | 50 | 51.55 |
| Dementia stage | Mild | 42 | 43.30 |
| | Moderate | 40 | 41.24 |
| | Severe | 15 | 15.46 |
| Age | Range | 61-88 | |
| | Mean \pm SD | 74.082 \pm 7.369 | |
| MMSE score | Range | 5-25 | |
| | Mean \pm SD | 16.773 \pm 5.610 | |
| Frequency of delirium* | Range | 0-6 | |
| | Mean \pm SD | 0.814 \pm 1.093 | |
| Frequency of BPSD* | Range | 0-6 | |
| | Mean \pm SD | 0.907 \pm 1.225 | |
| Frequency of clinic visits* | Range | 0-5 | |
| | Mean \pm SD | 1.825 \pm 1.362 | |
| Frequency of home consultations* | Range | 0-3 | |
| | Mean \pm SD | 0.371 \pm 0.870 | |
| Frequency of ER visits* | Range | 0-3 | |
| | Mean \pm SD | 0.835 \pm 0.921 | |
| Frequency of hospital admissions* | Range | 0-3 | |
| | Mean \pm SD | 0.320 \pm 0.550 | |

ER= emergency room, *Clinical events: recorded in the last 2 months before enrollment in the study.

Table (1b): Caregivers' characteristics

| N=97 | | N | % |
|-----------|---------------|--------------------|-------|
| Gender | Male | 34 | 35 |
| | Female | 63 | 65 |
| Age | Range | 22-67 | |
| | Mean \pm SD | 37.299 \pm 8.641 | |
| Education | Illiterate | 3 | 3.09 |
| | Preparatory | 1 | 1.03 |
| | Secondary | 51 | 52.58 |
| | University | 42 | 43.30 |
| Type | Family | 84 | 86.60 |
| | Paid | 13 | 13.40 |

Table (2): Assessment of caregiver stress among studied caregivers

Table (2a): Final score

| Zarit Burden Interview | N | % |
|---------------------------------------|---------------------|-------|
| No to mild burden (Score 0-10) | 4 | 4.12 |
| Mild to moderate burden (Score 11-20) | 27 | 27.84 |
| High burden (Score >20) | 66 | 68.04 |
| Range | 3-48 | |
| Mean \pm SD | 26.990 \pm 11.021 | |

Table (2b): Responses to individual questions of Zarit Burden Interview

| Question | Response | N | % |
|--|---------------|----|-------|
| 1. Not having time for yourself | Never | 6 | 6.19 |
| | Rarely | 27 | 27.84 |
| | Sometimes | 34 | 35.05 |
| | Frequently | 22 | 22.68 |
| | Nearly always | 8 | 8.25 |
| 2. Feeling stressed | Never | 4 | 4.12 |
| | Rarely | 22 | 22.68 |
| | Sometimes | 37 | 38.14 |
| | Frequently | 22 | 22.68 |
| | Nearly always | 12 | 12.37 |
| 3. Feeling angry | Never | 4 | 4.12 |
| | Rarely | 32 | 32.99 |
| | Sometimes | 31 | 31.96 |
| | Frequently | 20 | 20.62 |
| | Nearly always | 10 | 10.31 |
| 4. Affection of relationship with others | Never | 6 | 6.19 |
| | Rarely | 28 | 28.87 |
| | Sometimes | 35 | 36.08 |
| | Frequently | 18 | 18.56 |
| | Nearly always | 10 | 10.31 |

| | | | |
|--|----------------------|----|-------|
| 5. Feeling stressed | Never | 2 | 2.06 |
| | Rarely | 24 | 24.74 |
| | Sometimes | 35 | 36.08 |
| | Frequently | 21 | 21.65 |
| | Nearly always | 15 | 15.46 |
| 6. Feeling that your health has suffered | Never | 3 | 3.09 |
| | Rarely | 25 | 25.77 |
| | Sometimes | 31 | 31.96 |
| | Frequently | 25 | 25.77 |
| | Nearly always | 13 | 13.40 |
| 7. Not having as much privacy | Never | 5 | 5.15 |
| | Rarely | 26 | 26.80 |
| | Sometimes | 28 | 28.87 |
| | Frequently | 20 | 20.62 |
| | Nearly always | 18 | 18.56 |
| 8. Feeling that your social life has suffered | Never | 3 | 3.09 |
| | Rarely | 25 | 25.77 |
| | Sometimes | 30 | 30.93 |
| | Frequently | 20 | 20.62 |
| | Nearly always | 19 | 19.59 |
| 9. Loss of life control | Never | 1 | 1.03 |
| | Rarely | 23 | 23.71 |
| | Sometimes | 37 | 38.14 |
| | Frequently | 20 | 20.62 |
| | Nearly always | 16 | 16.49 |
| 10. Feeling uncertain about what to do | Never | 1 | 1.03 |
| | Rarely | 27 | 27.84 |
| | Sometimes | 31 | 31.96 |
| | Frequently | 22 | 22.68 |
| | Nearly always | 16 | 16.49 |
| 11. Feeling you should do more | Never | 1 | 1.03 |
| | Rarely | 17 | 17.53 |
| | Sometimes | 25 | 25.77 |
| | Frequently | 26 | 26.80 |
| | Nearly always | 28 | 28.87 |
| 12. Feeling you could do better in patient care | Never | 1 | 1.03 |
| | Rarely | 14 | 14.43 |
| | Sometimes | 25 | 25.77 |
| | Frequently | 29 | 29.90 |
| | Nearly always | 28 | 28.87 |

Table (3): Correlation between ZBI-A score and study variables

| Variable | r | P-value |
|---|----------|----------------|
| Patient age | 0.438 | <0.001* |
| MMSE score | -0.703 | <0.001* |
| Frequency of delirium episodes | 0.581 | <0.001* |
| Frequency of BPSD episodes | 0.443 | <0.001* |
| Frequency of clinic visits | -0.079 | 0.440 |
| Frequency of home consultations | 0.442 | <0.001* |
| Frequency of ER visits | 0.525 | <0.001* |
| Frequency of hospital admissions | 0.498 | <0.001* |
| Caregiver age | 0.282 | 0.005* |

ER= emergency room.

Table (4): Factors related to caregiver stress among studied caregivers

| | | ZBI-A score | | | | T-Test or ANOVA | |
|---------------------|-------------|-------------|--------|---|--------|-----------------|---------|
| | | N | Mean | ± | SD | T or F | P-value |
| Patient gender | Male | 61 | 27.918 | ± | 11.360 | 1.081 | 0.283 |
| | Female | 36 | 25.417 | ± | 10.388 | | |
| Patient education | Illiterate | 44 | 30.455 | ± | 9.663 | 2.173 | 0.078 |
| | Primary | 8 | 25.000 | ± | 12.972 | | |
| | Preparatory | 10 | 22.700 | ± | 10.100 | | |
| | Secondary | 23 | 24.739 | ± | 11.744 | | |
| | University | 12 | 23.500 | ± | 11.712 | | |
| Marital state | Widow | 48 | 28.729 | ± | 12.072 | 1.228 | 0.298 |
| | Married | 46 | 25.174 | ± | 9.799 | | |
| | Divorced | 3 | 27.000 | ± | 9.849 | | |
| Smoking | Current | 19 | 23.526 | ± | 12.598 | 1.327 | 0.270 |
| | Ex-Smoker | 28 | 28.750 | ± | 9.995 | | |
| | Non-Smoker | 50 | 27.320 | ± | 10.867 | | |
| Dementia Stage | Mild | 42 | 19.452 | ± | 7.939 | 40.187 | <0.001* |
| | Moderate | 40 | 29.925 | ± | 8.483 | | |
| | Severe | 15 | 40.267 | ± | 7.995 | | |
| Diabetes | Yes | 65 | 26.723 | ± | 11.150 | -0.338 | 0.736 |
| | No | 32 | 27.531 | ± | 10.910 | | |
| Hypertension | Yes | 78 | 27.179 | ± | 11.601 | 0.342 | 0.733 |
| | No | 19 | 26.211 | ± | 8.443 | | |
| Stroke | Yes | 36 | 27.361 | ± | 12.428 | 0.254 | 0.800 |
| | No | 61 | 26.770 | ± | 10.204 | | |
| ISHD | Yes | 22 | 25.500 | ± | 10.787 | -0.719 | 0.474 |
| | No | 75 | 27.427 | ± | 11.122 | | |
| Heart failure | Yes | 13 | 25.077 | ± | 12.359 | -0.671 | 0.504 |
| | No | 84 | 27.286 | ± | 10.851 | | |
| Renal disease | Yes | 7 | 22.429 | ± | 10.596 | -1.138 | 0.258 |
| | No | 90 | 27.344 | ± | 11.031 | | |
| Hepatic disease | Yes | 7 | 29.143 | ± | 12.628 | 0.535 | 0.594 |
| | No | 90 | 26.822 | ± | 10.949 | | |
| Caregiver gender | Male | 34 | 25.529 | ± | 10.930 | -0.958 | 0.340 |
| | Female | 63 | 27.778 | ± | 11.077 | | |
| Caregiver education | Illiterate | 3 | 30.333 | ± | 13.317 | 1.527 | 0.213 |
| | Preparatory | 1 | 41.000 | ± | 0.000 | | |
| | Secondary | 51 | 28.392 | ± | 10.702 | | |
| | University | 42 | 24.714 | ± | 11.079 | | |
| Caregiver type | Family | 84 | 26.988 | ± | 10.768 | -0.004 | 0.997 |
| | Paid | 13 | 27.000 | ± | 13.032 | | |

ZBI-A = Zarit Burden Interview-Arabic, ISHD=Ischemic heart disease

Table (5): Regression analysis model for risk factors associated with caregiver stress in the studied caregivers

| | Unstandard. Coeff. | | Standard. Coeff. | T | P val. |
|--|--------------------|-----------|------------------|--------|--------|
| | B | Std. Err. | Beta | | |
| Patient age | 0.098 | 0.118 | 0.066 | 0.836 | 0.405 |
| MMSE score | -0.686 | 0.341 | -0.349 | -2.012 | 0.047* |
| Caregiver age | 0.222 | 0.084 | 0.174 | 2.657 | 0.009* |
| Frequency of delirium episodes | 1.151 | 0.937 | 0.114 | 1.228 | 0.223 |
| Frequency of BPSD episodes | 1.313 | 0.636 | 0.146 | 2.065 | 0.042* |
| Frequency of home consultations | 1.570 | 0.959 | 0.124 | 1.637 | 0.105 |
| Frequency of ER visits | 1.514 | 1.009 | 0.127 | 1.501 | 0.137 |
| Frequency of hospital admissions | 2.612 | 1.740 | 0.130 | 1.501 | 0.137 |
| Dementia Stage | 0.285 | 2.751 | 0.019 | 0.104 | 0.918 |
| a. Dependent Variable: Zarit Burden Interview (total) | | | | | |

ER= emergency room