Caregivers’ burden and needed support for the care of dementia patients attending Ain Shams University hospitals

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Abstract

Background: Dementia in late stages affects patients’ life like being dependent, malnourished, having psychological and sleep problems. Caregivers face physical, financial, medical, and psychological burdens and are in need for support to complete caregiving responsibilities. Not all caregivers have the sufficient knowledge regarding how dementia affects the patients.

Aim: To determine the burden of caregiving process on caregivers of moderate to severe and severe dementia patients, the type of support and knowledge that caregivers need during this process

Methods: a cross-sectional study involving 101 caregivers of moderate to severe and severe dementia patients attending outpatient clinics and inpatients in Ain Shams University Hospitals. Demographic data of the patients and their caregivers were collected. A questionnaire was applied on caregivers including types of burden they experienced, types of support they needed and their knowledge about dementia & its effect on patients’ life.

Results: Most caregivers had different types of caregiving burdens. Ninety-eight percent (98%) of them had fear of future burden, 89% had physical& psychological burden and 69% had financial burden. Most caregivers needed support in caregiving. Eighty percent (80%) of them needed medical support, 59.4% needed physical support, 54.5% needed psychological support, 47.5% needed financial support, while only 8.9% needed social support. None of the caregivers had accurate previous knowledge about dementia. Ninety-three percent (93%) of caregivers predicted that dementia patients might need special care. Regarding dementia effect on patients, 88.1% of caregivers knew it had an effect on patients’ behavior, 74.3 % knew it affects sleep, 54.5% knew it affects safety, 53.5% agreed with its effect on patients’ activity and 48.5% knew it affects nutrition

Conclusion: Caregiving of moderate to severe and severe dementia patients is associated with huge physical, psychological and financial burdens. Most of the caregivers are in need of more support and knowledge to help them alleviate their burden and improve patients’ care and quality of life.

Keywords: dementia, caregivers, burden, support, knowledge.

Background

The Diagnostic and statistical manual of mental disorders-5 (DSM-5) characterizes dementia as a substantial impairment in one or more cognitive domains (memory, communication, language, attention, reasoning, and visual perception). This impairment must be sufficient to interfere with independence in everyday activities, not exclusively during delirium or explained by another mental disorder. (Edition F. DSM-5, 2013)

In Egypt, the prevalence of dementia among individuals aged ≥50 years was estimated to be 2.01%-5.07%. (Elshahidi et al., 2017). In USA, the number of aged 65 and older with Alzheimer's dementia (AD) by mid-century may grow to 13.8 million. This represents a steep increase from the estimated 5.7 million Americans who have Alzheimer’s dementia today.
Early on, the goal of dementia care is to preserve functional status. However, as the disease progresses, goals shift to maintaining the ability to live at home, maintaining mobility, reducing caregiver burden and controlling behavioral and psychological problems. (Alzheimer’s Association, 2018)

Caregivers of people with dementia may be less able to cope with stressors as they have high rates of financial, emotional and physical difficulties associated with caregiving. (Freedman & Spillman, 2014), Therefore, Caregivers of dementia patients have difficulty in maintaining social relationships with family and friends. They feel isolated and alone, lack familial and community supports, and express a need for social support. (Grigorovich et al., 2016)

Therefore we need to know the burden of dementia caregiving in moderate to severe and severe stages on Egyptian caregivers, which kind of support they are in need and their knowledge about the disease and its effect on the patients.

Results
The current study is a cross-sectional study. The study population was 101 caregivers of moderate to severe and severe dementia patients. Comprehensive geriatric assessment was applied on all selected patients.

Methods
The present study is a cross-sectional study that included 101 caregivers of moderate to severe and severe dementia patients according to Global Deterioration Scale (GDS) (Reisberg et al., 1982). They were interviewed at outpatient clinics and inpatients of Ain Shams University Hospitals after taking informed consent from them.

For patients: Comprehensive geriatric assessment was done including (detailed history; demographic data, medical history, drug history, dementia history and problems related to it, and application of Mini Mental State Examination (MMSE) (Folstein et al., 1975), Activities of Daily Living (ADL) (Katz et al., 1963) and Instrumental Activities of Daily Living (IADL) (Lawton et al., 1969).

For caregivers: the following data were collected through a questionnaire that was applied on caregivers which included, the presence of any burden (physical, financial and psychological), type of support needed (medical, physical, psychological, financial and social) and their knowledge about dementia & its effect on sleep, nutrition, behavior and activity.

Analysis of data was performed by using the 23rd version of Statistical Package of Social Science (SPSS). Description of all data in the form of mean (M) and standard deviation (SD) for all quantitative variables. Frequency and percentage for all qualitative variables. Comparison of qualitative variables was done using Chi-square test or Fisher Exact.

Significance level was determined according to P-value (Probability): P≥ 0.05 is insignificant, P< 0.05 is significant and P< 0.01 is highly significant.

The study was performed in adherence to the principles established by the Declaration of Helsinki and the study methodology was reviewed and approved by Ethical Committee of Scientific research and the Research Review Board of the Geriatrics and Gerontology Department, Faculty of Medicine, Ain Shams University. Informed verbal consent was obtained from all the participants because some of the participants were illiterate and could not provide signed consent.

The ethics committee approved using verbal consent.

The mean age of the study participants was 73.7±6.44 years. All of them reported living at their homes mostly receiving caregiving services (98%) from at least one caregiver (57.4%). Most of them were females (71.3%), widow/widower (67.3%), illiterate (53.5%) and reported having a sufficient income (52.5%) (Table 1).

Most of the patients had severe dementia (GDS=7, 60.4%) with a mean MMSE of 15.6 ± 3.53, totally dependent in IADL (59.4%) and ADL (47.5%). (Table 2)

Socio-demographic data from all caregivers were obtained. Their mean age was 46.4 years, 81.2% were first-degree relatives to the patients, 70.3% were females, 62.4% got post-secondary education, 57.4% provide both physical and financial support, 52.5% of patients have multiple caregivers, 53.5% are part-time caregivers and 5.9% had previous caregiving experience for dementia patients. No one had previous training for dementia care. (Table 3)
### Table (1): Socio-demographic data of dementia patients:

|                          | Min. | Max. | Mean | SD  |
|--------------------------|------|------|------|-----|
| Age                      | 60.00| 86.00| 73.70| 6.44|
| Sex Male                 | 29   |      | 28.7%|     |
|                          | Female| 72   | 71.3%|     |
| Marital status Married   | 31   |      | 30.7%|     |
| Widow/ Widower           | 68   |      | 67.3%|     |
| Divorced                 | 2    |      | 2.0% |     |
| Education level Illiterate| 54   |      | 53.5%|     |
| Primary                  | 26   |      | 25.7%|     |
| Secondary                | 12   |      | 11.9%|     |
| Post-secondary           | 9    |      | 8.9% |     |
| Income Sufficient        | 53   |      | 52.5%|     |
| Not sufficient           | 48   |      | 47.5%|     |
| Living place Home        | 101  |      | 100.0%|   |
| Living With whom         |      |      |      |     |
| Alone                    | 2    |      | 2.0% |     |
| With caregiver           | 99   |      | 98.0%|     |
| Residence Urban          | 93   |      | 92.1%|     |
| Rural                    | 8    |      | 7.9% |     |
| Number of those who can take care of patient 1 | 58 | | 57.4% | |
|                          | 2    |      | 36.6%|     |
|                          | 3    |      | 5.9% |     |

*Income classified sufficient or not according having financial problem or not.

### Table (2): Cognitive and Functional assessment of patients:

|                          | Min. | Max. | Mean | SD  |
|--------------------------|------|------|------|-----|
| Mini Mental State Examination | 8.00 | 20.00| 15.65| 3.53|
| Activities of Daily Living |      |      |      |     |
| Totally dependent        | 48   |      | 47.5%|     |
| Assisted                 | 22   |      | 21.8%|     |
| Independent              | 31   |      | 30.7%|     |
| Instrumental Activities of Daily Living |      |      |      |     |
| Totally dependent        | 60   |      | 59.4%|     |
| Assisted                 | 27   |      | 26.7%|     |
| Independent              | 14   |      | 13.9%|     |
| Global Deterioration Scale | 5.00 | 18   | 17.8%|     |
|                          | 6.00 | 22   | 21.8%|     |
|                          | 7.00 | 61   | 60.4%|     |

### Table (3): Socio-demographic data of caregivers:

|                          | Min. | Max. | Mean | SD  |
|--------------------------|------|------|------|-----|
| Caregiver age            | 22.00| 80.00| 46.42| 13.76|
| Caregiver sex Male       | 30   |      | 29.7%|     |
|                          | Female| 71   | 70.3%|     |
| Caregiver Education Illiterate| 6    |      | 5.9% |     |
| Primary                  | 13   |      | 12.9%|     |
| Secondary                | 19   |      | 18.8%|     |
| Relation to the patient Post-secondary | 63 | | 62.4% | |
| First degree             | 82   |      | 81.2%|     |
| Other degree             | 19   |      | 18.8%|     |
| Not a relative           | 0    |      | 0%   |     |
| Multiple caregivers for a patient Yes | 53 | | 52.5% | |
|                          | No   | 48   | 47.5%|     |
| Care-giving time         |      |      |      |     |
| Part time                | 54   |      | 53.5%|     |
| Support type offered by caregivers |      |      |      |     |
| Full time                | 47   |      | 46.5%|     |
| Physical support         | 22   |      | 21.8%|     |
| Financial support        | 21   |      | 20.8%|     |
| Both                     | 58   |      | 57.4%|     |
| Previous training        |      |      |      |     |
| Yes                      | 0    |      | 0%   |     |
| Previous caregiving      |      |      |      |     |
| No                       | 101  |      | 100.0%|   |
| Yes                      | 6    |      | 5.9% |     |
|                          | No   | 95   | 94.1%|     |
Caregivers were asked about the burden they face during dementia care and showed that the commonest reported burden was fear of future burden (98%), then feeling physical burden (89.1%), psychological burden (89.1%) and the least common was the financial burden (69.3%). (Table 3)

Regarding the needed support to decrease this burden, the commonest reported needed supports was medical support (80.2%), followed by physical support (59.4%), psychological support (54.5%), financial support (47.5%) and the least needed was social support (8.9%). (Table 4)

From caregivers’ perspectives, 93.1% know that dementia patients may need special care, 88.1% know that dementia affects behavior, 74.3% of caregivers know that dementia affects sleep, 54.5% know that dementia affects patient’s safety, 53.5% know that dementia affects activity, and 48.5% know that dementia affects nutrition. No one of the caregivers had previous knowledge about dementia or required care. (Table 5)
Discussion:
Dementia is an incurable disorder for which traditional health outcome measures (e.g., disease remission, prolonged survival) are often unachievable or hold little meaning. Although a variety of measures have been developed that assess control of behavioral symptoms and caregiver outcomes, these may not capture everything that may be important to patients and their caregivers as they face the behavioral, medical and social consequences of dementia. (Jennings, et al., 2017)
Increasing numbers of cases will pose undue burden on individuals who have dementia, their caregivers, and healthcare systems more generally. So surveys should be done to estimate this burden, help to relieve it and improve patients’ quality of life. (Nichols et al., 2019)

In this study, 98% of our studied population had fear of future burden. This agrees with the results of a study done by Givens et al., (2012) which reported that the uncertainty about the future may create an ambiguous situation for family members and increase the burden on the caregiver.

Burden has several forms either physical or psychological or financial. Regarding our population, the most prevalent burden was the physical one (89.1%) and 98% caregivers reported their need for physical support. In Krutter et al., (2020) they reported a similar burden as 98% of the caregivers of dementia patients and home-care nurses complained of physical burden. One of the most common causes of burden reported by Liu et al., (2017) is that the lower functional status of the patient which was associated with higher caregiver burden, lower life satisfaction, and higher degrees of depression and anxiety.

Regarding psychological burden among our studied population, it affects 89.1% of them and 54.5% reported the need for psychological support.

In agreement with our results Krutter et al., (2020) reported that 99% of caregivers for dementia patients had a psychological burden. As behavioral problems associating dementia may increase psychological burden, it was found that emotional support for caregivers who have difficulty in coping with behavioral problems may enhance therapeutic engagement and their readiness to use behavior management strategies. (Gitlin & Rose 2014).

Psycho-educational approaches are most effective at improving caregiver knowledge, reducing caregiver burden and depression symptoms, and increasing subjective well-being and caregiver satisfaction. (Sörensen et al., 2006)
The least reported burden among the studied population was the financial one. The prevalence of financial burden was 69.3% and 47.5% of dementia caregivers needed financial support. That’s because dementia has huge economic impact on people living with the illness, their Caregivers, and society as a whole. Better support for people with dementia and their caregivers, as well as fair and efficient financing of social care services, are essential to address the current and future challenges of dementia. (Wittenberg et al., 2019)
The current study revealed that 98% of the studied population feel the need for some sort of support. In the same way, Maki et al., (2018) agreed that support for dementia patients should be provided with medical social workers who are responsible for coordinating community care by linking people with dementia and their caregivers with community sources. Caregivers are considered as team members to provide support in daily living.

Medical support was important for 80.2% of the studied population. Therefore, Hum et al., (2014) made attention to family physicians who can coordinate care across health sectors, community services, and health professionals and consider solutions to individuals’ and caregivers’ problems across the stages and transitions of dementia, including advance care planning.

Dementia caregivers are at an increased risk of various health problems including higher levels of chronic conditions such as diabetes, arthritis, ulcers, anemia, cardiovascular problems, lower immunity, and poorer self-rated health. They need more doctor visits and use of prescription medications and showed decreased engagement in preventative health behaviors such as exercise. They also have greater likelihood of drinking alcohol, smoking, and poor sleep patterns. (Schulz & Martire, 2004). So medical support for both patients and their caregivers is of great paramount.

No one of the studied population had previous information about dementia progression or had previous discussion about goals of care for dementia patients. In the same way, Glynn et al., (2017) study in Ireland about public knowledge and understanding of dementia showed a poor level of information among the studied population.

But in the Australian population, a survey done investigating knowledge about dementia, its risk
factors and burden showed that 82% of the studied population had good knowledge. That is due to the role of media in focusing on dementia symptoms and burden. (Low & Anstey, 2009)

Wang et al., (2018) proved that the limited availability of dementia-specific continuing education programs is an important contributing factor to the lower level of knowledge about dementia among caregivers.

Raising public knowledge of dementia is crucial for optimizing care, enhancing the quality of life of dementia patients, and decreasing the caregiving burden. Increasing knowledge levels will help to tackle the stigma of dementia and open up a better informed-debate about the needs of these patients. (Rimmer et al., 2005)

This study revealed that 93.1% of caregivers agreed that dementia patients may need special care. Prevalence of caregivers who knew that dementia may affect patients’ behavior, sleep, safety, activity and nutrition was 88.1%, 74.3%, 54.5%, 53.5% and 48.5% respectively. Most of their knowledge emerged during caregiving process either than previous education.

In the same way, Caregivers proved that various symptoms of dementia may affect the quality of life of the elderly with dementia. Pereira & Soares, (2015) showed that neuropsychiatric symptoms, depression, and poor sleep quality in elderly people with dementia lead to loss of autonomy and independence.

Knowledge of dementia is evinced to be a protective factor against caregivers’ subjective distress. This reinforces the need for caregivers to improve their understanding towards dementia even if they have been a caregiver for a prolonged period of time. (Sörensen & Conwell, 2011)

Conclusions

This study shows that caregivers of dementia patients face high rates of psychological, physical, and financial burden. They are in need of more support. Knowledge about dementia is poor among the studied population. So, further studies are needed to investigate the causes of poor knowledge and the ideal ways to deliver health education that should be applied to all caregivers.

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