

The Level of Function of Dementia Patients has an Impact on the Caregiver Burden

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Abstract

Introduction: Caregivers of patients with Alzheimer's disease (AD) suffer from psychological and financial burdens. However, the results of the relationship between burden and functional decline have remained inconsistent. Therefore, the aim of this study was to examine the impact of the level of function of dementia patients on the caregiver burden.

Methods: A cross-sectional study was conducted in a sample comprised of Ninety-six primary caregiver of elderly patients with dementia. The cognitive function, functional impairments, depressive symptoms for patients and then caregiver burden were assessed.

Results: Caregiver burden was investigated using Zarit Burden Interview (ZBI) investigated care giver burden, showed that (38.9%) of the caregivers suffered from severe burden, (37.9%) suffered from moderately severe burden and as regard care recipients' dependency in basic Activities of Daily Living (ADL) the mean score was 3.68 ± 1.76 indicating moderate to high dependency, it was found that more functional impairment was significantly associated with higher caregiver burden as ZBI were significantly inversely (negatively) correlated with ADL and IADL of care recipients

Conclusion: Functional decline of care recipients associated with more care giver burden

Keywords: Caregiver; Dementia; Depressive symptoms; Activities of daily living

Introduction

Care giving for persons with dementia is a global issue, in part because today, over 46 million people live with dementia worldwide [1].

Caregiver burden (CB) has been defined as a multidimensional response to physical, psychological, emotional, social and financial stressors associated with the care giving experience [2]. Family members caring for people with dementia at home often describe the experience as "enduring stress and frustration" [3].

CB is associated with poor outcomes for caregivers such as depression, illness, and decreased quality of life [4] and poor outcome for dementia patients such as poor quality of life and early nursing home placement [5].

Researchers have found that the degree of burden experienced by caregivers depends on several contextual factors, care giving-related factors and primary stressors including the socio-demographical status of caregivers and care-recipients, disease progressions suffered by the care-recipient and the perceived stress resulting from care giving [6]. patient-related factors such as performance of activities of daily living (ADLs) have been related to burden [7].

Caregivers were expected to experience high levels of stress when they do not have sufficient internal (information, skills, coping behaviors) and external (finances, help from other family, formal care) resources to adapt to care-giving situations [8].

Studies conducted to assess the difference of burden among males and females, showed that the female family caregivers perceived less social support and experienced higher degrees of caregiver burden compared to male caregivers [9]. A meta-analysis of gender differences in caregiving suggests that female caregivers perform more personal care tasks for their impaired relative, such as toileting and bathing, as well as more household chores, and these tasks may bear a stronger relationship to caregiver burden [10].

Materials and Methods

A cross-sectional study (96 primary caregiver of patients with dementia) was conducted among primary caregivers of the demented elderly subjects 60 years and older, both males and females, who were clinically diagnosed with dementia according to Diagnostic and Statistical Manual of Mental disorders IV (DSM IV) criteria with exclusion of caregivers who suffer from any pre-caregiving psychiatric or neurologic disorder and who were not co-resident with the care-recipient. Participants were recruited from Ain Shams University Hospital. Informed consent was obtained from all participants and the study was approved by the ethical committee of the faculty of medicine Ain Shams University. All patients were subjected to detailed medical history, Mini-Mental State Examination [11]. Activities of daily living (ADLs) [12], Instrumental activities of daily living (IADLs) [13], the Cornell Scale for Depression in Dementia [14] and each caregiver was subjected to detailed interview to assess socio-demographic data., Zarit Burden Interview (Arabic version) [15], Activities of daily living (ADLs), Instrumental activities of daily living (IADLs), The State - Trait Anxiety Inventory (STAI) (Arabic version) [16].

Data analysis

Description of all data in the form of mean (M) and standard deviation (SD) for all quantitative variables was done. Correlation analysis (using Pearson's method) to assess the strength of association

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between two quantitative variables. Significance level measured according to P value (probability), P>0.05 is insignificant, P<0.05 is significant and P<0.01 is highly significant.

Results

The caregivers' mean age was (42.94) ± 13.17 years. (69.7%) of them were women and (30%) were men. (52%) of them, were married. Most of them (47.9%) were highly educated, the monthly income for more than half of them (68.7%) was enough, the mean age for care recipients was (76.72) ± 6.41 years (Table 1). 47.4% of care recipients were definitely suffering from Major depressive disorder. Mini Mental State Examination (MMSE) mean score was 18.42 ± 5.82 indicating that the cognitive state of care recipients in our sample ranged from Mild Cognitive Impairment to Severe Cognitive Impairment, and as regard care recipients' dependency in basic Activities of Daily Living (ADL) the mean score was 3.68 ± 1.76 indicating moderate to high dependency and so in Instrumental Activities of Daily Living (IADL) as showed by mean score 4.42 ± 2.05. (ZBI), which showed that (38.9%) of the caregivers suffered from severe burden and State-Trait Anxiety Inventory 1 (STAI-1) the mean score was 29.71 ± 4.03 and STAI-2 mean score was 28.77±5.18 (Table 2). STAI-1, STAI-2 and ZBI were significantly inversely (negatively) correlated with MMSE, ADL and IADL but not significantly correlated with patient Cornell score except for ZBI which had significant positive correlation (Table 3).

Variables		Mean/N	SD/%
Gender	Male	29	30%
	Female	67	69.70%
Age		42.94	13.71
Marital status	Unmarried	46	47.90%
	Married	50	52%
Education	Non-Educated	13	13.50%
	Middle	37	38.50%
	High	46	47.90%
Monthly income	Hardly enough	24	25%
	Enough	66	68.70%
	Enough with ease	6	6.30%
Age of care recipient by years		76.72	6.41

Table 1: Descriptive analysis of caregivers demographic data.

Variables		Mean/N	SD/%
Cornell scale for depression in dementia	Probably MDD	42	44.20%
	Definite MDD	45	47.40%
	No MDD	8	8.40%
MMSE score for care recipients		18.42	5.82
ADL score for care recipients		3.68	1.76
IADL score for care recipients		4.42	2.05
ZBI for caregivers	Little or No burden	6	6.30%
	Mild to moderate burden	16	16.80%
	Moderate to severe burden	36	37.90%
	Severe burden	37	38.90%
STAI-1 Scoring for caregivers		29.71	4.03
STAI-2 Scoring for caregivers		28.77	5.18

Table 2: Descriptive analysis of care recipient and caregivers investigated scores.

Care givers	Care recipient	MMSE score	ADL score	IADL score	Cornell Total Score
STAI-1	Pearson Correlation	-0.359	-0.233	-0.273	0.06
	P-Value	<0.001	0.023	0.007	0.566
	Sig.	S	S	S	NS
STAI-2	Pearson Correlation	0.247	0.396	0.278	-0.17
	P-Value	0.016	<0.001	0.006	0.101
	Sig.	S	S	S	NS
ZBI total score	Pearson Correlation	-0.472	-0.204	-0.357	0.365
	P-Value	<0.001	0.047	<0.001	<0.001
	Sig.	S	S	S	S

Table 3: Correlation between STAI-1 and ZBI scores and care recipients' scores.

Discussion

Caring for a family member with AD or other dementing illness poses significant challenges, and many studies report considerable psychological and physical morbidity among caregivers compared to age-matched controls [17]. There are care recipients' characteristics that determine the severity of caregiver's burden such as: cognitive impairment (including memory loss and deterioration in higher cortical functions); functional impairment (including difficulty with basic activities of daily living (ADL) such as bathing and toileting, as well as instrumental ADL such as keeping a checkbook); and behavioral and psychiatric impairment (including agitation, delusions and hallucinations, and disinhibition) [18].

This study examined which factors were more significant predictors of caregiver burden. The results indicated that caregiver burden had a nearly equal strong association with functional impairment, cognitive function and depression and so it is important to follow those caregivers periodically and give advice about ways of relief.

The study included 96 caregivers aged 20 or older who were the primary caregivers for demented older family members. Most of them (69.7%) were females and (30%) were males with mean age (42.94) ± 13.17 years and this goes in accordance with Lin and Wu [19] who examined 956 caregivers and found out that 69.9% of them were females.

In this study 47.4% of the demented care recipients were definitely depressed according to Cornell depression scale disorder while (44.2%) of them were probably suffering from Depression and only (8.4%) were not depressed, and this goes in accordance with other studies that demonstrated that the rates of depressive symptoms among community-dwelling demented elderly range from 16 to 38% and the rates of sub-threshold or 'non-major depression' (minor subsyndromal and recurrent brief depression) range from 9 to 31% among community-based demented elderly [20-23].

Burden is a multidimensional construct [24], comprising objective burden, which is the practical care of the person with dementia such as supervision and helping with daily tasks, and subjective burden, which may be divided further into personal strain and role strain [25]. The most widely used scale to measure burden is the 22-item Zarit Burden Scale, which has high internal consistency and good test-retest reliability [26]. So in this study we investigated Caregiver Burden using Zarit Burden Inventory (ZBI) which showed that (38.9%) of the caregivers suffered from severe burden, (37.9%) suffered from moderately severe burden, (16.8%) suffered from mild These results differs mildly from results obtained from other authors such as Loureiro [27] who found that

(61.5%) of the family caregivers had moderate to mild burden, (23.1%), moderate to severe burden, and (15.4%) had no burden noted. In our study there was no statistically significant difference between those who had severe burden and those who had moderated burden.

Although the negative aspects of caregiving for people with dementia tend to receive most attention, but caring has also been associated with positive feelings and outcomes [28].

Sanders [29] reported that between 55% and 90% of caregivers experienced positive experiences such as enjoying togetherness, sharing activities, feeling a reciprocal bond, spiritual and personal growth, increased faith, and feelings of accomplishments and mastery.

Care-recipient factors were more significant predictors of caregiver burden than caregiver- or caregiving-related factors [30], and this goes in accordance with our findings as we found a statistically significant correlation between caregivers' score in ZBI and care-recipient scores in the MMSE, ADL, IADL and Cornell Scale for Depression in Dementia because any decline in basic activities of daily living, instrumental activities of daily living and mini-mental state examination requires a higher level of caregiver engagement and devotion to manage daily life activities because of increasing dependence of care-recipients, these results supported by other studies which found out that the more impaired the care-recipients were in terms of either activities of daily living or instrumental activities of daily living or cognitive impairment as evaluated by MMSE, the greater the burden reported by caregivers [31].

But others disagreed this may well be a reflection of the differing methodologies employed by researchers and the focus of some researchers on single variables, many studies focus on the immediate factors such as the impact of the cognitive deficits, help with everyday functioning and behavioral and psychological factors without considering variability within the caregiver such as personality factors or aspects outside of the caregiver/ patient dyad such as family relationships and support network [32,33].

Caregivers' anxiety state is investigated using STAI-1 and there was statistically significant correlation between state of anxiety and care-recipients' scores in ADL, IADL, MMSE and this goes in with other studies who found that caregivers of people with dementia experience high rates of clinically significant anxiety (10% to 35%) [34], that may also contribute to worsening the physical health status of caregivers, by increasing their vulnerability to develop diseases and reducing life expectancy itself [35].

Conclusion

In conclusion, caregiver burden had a stronger association with functional impairment. Therefore, interventions to help maintain function in patients with dementia may alleviate caregiver burden and improve caregiver well-being.

Recommendations

1. Educational and relational support to caregivers to reduce the negative burden of care.
2. Organization of respite services throughout the day that would allow the primary caregiver more time for leisure and personal care.
3. Enhancement of caregivers' awareness that by dedicating more time to themselves, they might not only reduce depression and anxiety, but provide better care.

4. Encouragement of caregivers to attend support groups where these are available and work toward establishing such groups.
5. Encouragement of involvement of other family members and volunteers in caring.
6. Extension of the research using qualitative methods to better highlight the extent of caregivers' problems.

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