Association of functional disability in dementia patients with caregiver stress: a cross-sectional study

ORIGINAL ARTICLE

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ABSTRACT

Background. Caregiver stress is a major issue in dementia care, for which behavioural and psychological symptoms of dementia (BPSD) are the main causes.

Objective. We aimed to determine whether functional disability (measured by the Disability Assessment for Dementia [DAD] scale) in dementia patients correlate with caregiver stress, independent of BPSD.

Methods. 88 subjects and their family caregivers recruited from memory and psychogeriatric clinics were assessed using the Clinical Dementia Rating scale (CDR), the Barthel Index (BI), the Mini-Mental States Examination (MMSE), the Neuropsychiatric Inventory (NPI), the Disability Assessment for Dementia (DAD) scale, the Geriatrics Depression Scale (GDS), and the Zarit Burden Interview. Correlations between caregiver stress and patient variables were studied using univariate and multiple regression analyses.

Results. 61% of the patients had Alzheimer's disease, and 73% had mild dementia (CDR=1). Caregiver stress correlated negatively with the DAD scale, and positively with the NPI and GDS, but not with the BI or MMSE. In multiple regression analysis, the BPSD, DAD, and GDS were all independently associated with caregiver stress.

Conclusions. The DAD scale is an appropriate tool for evaluating functional disability in dementia patients, as it correlates with caregiver stress better than the BI, and is independent of the GDS and NPI.

Key words: Caregivers; Dementia; Disability evaluation; Stress, psychological

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INTRODUCTION

Caring for a relative with dementia is stressful and associated with physical and mental health problems of the caregiver as well as an increased likelihood of abuse from their charge.[1] Caregiver stress is the extent to which caregivers perceive their emotional or physical health, social life, and financial status as suffering as a result of caring for their relatives.[2] The behavioural and psychological symptoms of dementia (BPSD) may have a primary role in caregiver stress.[3] Other predictors of high caregiver stress levels include: female gender, the amount of social support received, the caregivers' physical and mental state, and their personality and coping style.[4,5] Increased caregiver stress correlated with BPSD and negative symptoms (such as withdrawal and apathy).[6] Caregiver stress is a major determinant of community-based service utilisation and institutionalisation of dementia patients.[4,7]

Dependency in basic and instrumental activities of daily living (ADL) is another predictor of caregiver stress, but generally no direct relationship is found.

Instrumental ADL deficits begin in early stage of dementia, and basic ADL deficits increase with the severity of dementia, but many BPSD decrease in late stage of dementia.[8] We therefore examined the relationship between BPSD, functional disability, and caregiver stress to determine whether functional disability (measured by the Disability Assessment for Dementia [DAD] scale) was as important as BPSD in causing the caregiver stress.

METHODS

88 Chinese dementia patients and their adult family caregivers were recruited from 2 memory clinics and a psychogeriatric clinic in Hong Kong by convenience sampling. Eight patients refused to join the study. All recruited patients were living at home and had mild-to-moderate dementia (Clinical Dementia Rating Scale[9] [CDR] 1 or 2). Those living in residential care homes or having rapidly evolving symptoms in the recent 3 months were excluded. The caregivers were living with the patient or had visited the patient ≥4 times per week with an average caring time of >20 hours per week. Foreign domestic helpers were excluded, as we aimed to identify the determinant of caregiver stress in the Chinese community.

Recorded demographics included patient and/or caregiver gender, age, educational level, living arrangement, caregiver's relationship to the patient, and amount of social support received. Caregivers also provided estimates of when they noticed symptoms in patients and began to provide practical assistance for calculation of duration of illness and caring, respectively.

Diagnosis and staging of dementia (Alzheimer, vascular or mixed type) were assessed by trained geriatricians or psychogeriatricians. The CDR assessed performance in 6 domains: memory, orientation, judgement and problem solving, home and hobbies, community affairs and personal care.[9] The level of impairment in each domain was rated: 0=none, 0.5=questionable, 1=mild, 2=moderate, 3=severe. The global CDR score ranged from 0 (no dementia) to 3 (severe dementia).

Written informed consent was obtained from each subject and caregiver. The study was approved by the ethics committee of the Chinese University of Hong Kong and the Hospital Authority, New Territories East cluster.

Measurements

The Mini-Mental State Examination[10,11] (MMSE) was used to assess global cognitive ability. Lower overall scores indicated greater cognitive impairment. The highest possible score was 30.

The Barthel Index[12] was used to assess functional performance. The 10 basic ADL items included feeding, personal hygiene, dressing, toileting, bathing, transfer, walking, stair climbing, bowel control, and bladder control. The total score was 100. Higher scores indicated more independence in ADLs.

The DAD scale[13,14] was used to assess the patient's performance in basic and instrumental ADL, as well as leisure tasks. Assessment takes 15 to 20 minutes and requires no special training. Caregivers were asked to indicate performance of the patient by yes, no or not applicable. Higher scores represented less functional disability. In addition, the ability of the patient to initiate, plan and execute each task was also evaluated.

The Neuropsychiatric Inventory[15,16] (NPI) was used to assess behavioural symptoms in dementia patients. It evaluated 12 neuropsychiatric disturbances: delusions, hallucinations, agitation, depression, anxiety, apathy, irritability, euphoria, disinhibition, aberrant motor behaviour, night-time disturbances, and appetite and eating abnormalities. The severity and frequency of each symptom were rated by the caregivers. The highest possible score was 144.

The Geriatric Depression Scale (GDS)[17] was used to measure self-rated depression symptoms. The cut-off score was 7. Scores of >7 indicated significant depressive symptoms and warranted further investigation.

The Zarit Burden Interview[18] was used to assess the subjective burden of caregivers. It covered 22 aspects pertaining to the caregiver's health, psychological well-being, finance, social life, and relationship between the caregiver and the impaired person. The caregiver indicated how much discomfort each item caused from 'not at all' to 'extremely'. Higher scores indicated greater caregiver stress.

Spearman and Pearson correlation analyses were used to evaluate the strength of associations between caregiver stress and the severity of dementia, MMSE, GDS, NPI, BI and DAD scores. Stepwise multiple linear regression analysis was used to ascertain if the association of DAD scale with caregiver stress was independent of GDS and NPI.

RESULTS

88 patients (mean age, 79 years) and their caregivers were recruited (**Tables 1 and 2**). 63% of the patients were female. 61% had Alzheimer's disease, and 74% had mild dementia (CDR=1). The mean duration of dementia was 23 months. 89% of the patients were living with their family and cared by their spouse and/or children. 84% of the caregivers were female; 52% were children of the patients. The mean duration of caregiving was 15 months. 33% of the caregivers had not received any social support such as family support, home help services, respite care, and self-help group support.

Regarding the DAD scale, the commonest limitation in patients' performance was efficiency of completing the tasks (97%) and IADL (97%), followed by planning and organisation (96%), motivation (90%), leisure (72%), and ADL (59%) [**Table 3**].

Caregiver stress correlated negatively with the total and all sub-scores of DAD (**Table 4**), and positively with the GDS score and all sub-scores of the NPI except in hallucination, anxiety and euphoria. Caregiver stress did not correlate with BI or MMSE scores.

Stepwise multiple linear regression analyses

Table 1
Patient characteristics (n=88)

Variable	No. (%) of patients
Female	55 (63)
Mean±SD age (years)	79±6
Educational level	
No formal education	44 (50)
Primary	37 (42)
Secondary	7 (8)
Living arrangement	
Lives alone	8 (9)
Lives with family	78 (89)
Lives in housing flat for elderly	2 (2)
Mean±SD duration of dementia (months)	23±16
Diagnosis of dementia	
Alzheimer's disease	54 (61)
Vascular	20 (23)
Mixed	14 (16)
Severity of dementia (Clinical Dementia Rating)	
Mild (1)	65 (74)
Moderate (2)	23 (26)
Mean±SD cognitive, impairment and behavioural scores (range)	
Geriatric Depression Scale Scores (0-15)	6±3
Mini-Mental State Examination scores (0-30)	16±6
Barthel Index (0-100)	96±9
Chinese Disability Assessment scale for Dementia (0-100)	65±23
Neuropsychiatric Inventory (0-144)	14±17
Zarit Burden Interview (0-88)	33±18

Table 2
Caregiver characteristics (n=88)

Variable	No. (%) of caregivers
Female	74 (84)
Caregiver relationship to patient	
Spouse	19 (22)
Children	46 (52)
Relatives	20 (23)
Home-helper	3 (3)
Mean±SD duration of caregiving (months)	15±11
Social support	
None	29 (33)
Family support (informal)	49 (56)
Home helper service (formal)	10 (11)

Table 3
Activities of daily living (ADL) as measured by the Disability Assessment for Dementia (DAD) scale (n=88)

DAD scale	No. (%) of patients with limitation	Mean±SD score*
ADLs	52 (59)	85±20
Instrumental ADLs	85 (97)	44±30
Leisure	63 (72)	31±45
Motivation	79 (90)	70±25
Planning and organisation	84 (96)	64±22
Efficiency of completing the tasks	85 (97)	60±24

* Mean scores are expressed as percentages

Table 4
Correlations between caregiver stress and variables

Variable	Correlation coefficient *(r)*	P value
Severity of dementia (Clinical Dementia Rating scale)	0.282	0.008†
Mini-Mental States Examination score	-0.196	0.068
Geriatrics Depression Scale score	0.352	0.001†
Barthel Index	-0.183	0.087
Neuropsychiatric Inventory score	0.499	0.000†
Disability Assessment for Dementia (DAD) total score	-0.420	0.000†
DAD sub-score		
Activities of daily living	-0.460	0.000†
Instrumental activities of daily living	-0.374	0.000†
Leisure	-0.214	0.045*
Motivation	-0.337	0.001†
Planning and organisation	-0.505	0.000†
Efficiency of completing the tasks	-0.365	0.000†

* $p<0.05$ correlation is significant at the 0.05 level (2-tailed)
† $p<0.01$ correlation is significant at the 0.01 level (2-tailed)

were performed to identify the relationship between caregiver stress and the patient's cognitive and non-cognitive disturbances (**Table 5**). The BPSD, disability in ADL, and GDS scores were all independently associated with caregiver stress. After adjustment for GDS and NPI, DAD scores remained significantly associated with the Zarit Burden Interview scores (regression coefficient, -0.205; p=0.007).

DISCUSSION

Our findings on the high correlation between NPI scores and caregiver stress echoed those reported in other studies,[3,6,19] which showed that BPSD and negative symptoms (withdrawal and apathy) highly correlated with caregiver stress.

Impairment in basic and instrumental ADL (as measured by the DAD scale) also correlated well with caregiver stress, as both involved ability to perform, initiate, plan and execute tasks. This was contrary to a previous study that found no direct relationship between caregiver stress and deficits in ADL.[19] This difference might be due to the sensitivity of the assessment tools. The tool used in the previous study might have been too generic and not sensitive to functional loss resulting from cognitive deficits in demented patients. In our study, the correlation between basic ADL in DAD and caregiver stress was very strong, but the BI, which measured the same parameter, showed a non-significant correlation. The DAD was more sensitive for evaluating functional performance of dementia patients, as it evaluated both basic and instrumental ADL as well as performance in leisure activities. It included assessment of initiation and planning, which is typically poor (even in mild disease). As such, measurement in mild-to-moderate dementia using the BI would be limited by a ceiling effect, as most patients in this group could complete the task with supervision or encouragement, but might lack initiation or planning, which is not measured by the BI.

Depressive symptoms (as measured by the GDS) were associated with caregiver stress. Depression in dementia was one of the predictors of carer stress.[19] Depression is common in persons with dementia and might present differently than in those with normal cognition. It is therefore important for clinicians to ask about symptoms and start treatment early to reduce patient suffering and caregiver stress.

Cognitive impairment (as measured by the MMSE) was not a strong predictor of caregiver stress, but the CDR, which is a more clinical and general measurement of dementia severity, was. This suggested that poor cognition per se (such as poor performance on the serial-7 or not being able to tell the place or days of the week) was not the main concerns of caregivers. Rather, deficiencies in social participation and personal care cause caregiver stress.

The limitation of this study was its cross-sectional design, which does not allow for analysis of trends over time or assessment of causal relationships. Selection bias might also have been a problem, because these patients were recruited from memory and psychogeriatric clinics, which are tertiary facilities in Hong Kong. They might not represent patients treated in primary care settings or not treated at all. Moreover, the findings may not be applicable to severe dementia, as our study had few such patients. Thus, in severe dementia patients, an association between DAD scale and caregiver stress cannot be concluded.

CONCLUSION

Caregiver stress is a major issue, particularly as there is an increasing prevalence of dementia. Identifying

Table 5
Multiple linear regression analyses on the relationship between caregiver stress and cognitive and non-cognitive patient characteristics*

Covariate	Coefficient B	Beta	p Value
Neuropsychiatric Inventory score	0.349	0.332	0.001
Disability Assessment for Dementia score	-0.205	-0.263	0.007
Geriatrics Depression Scale score	1.296	0.242	0.009

* The partial regression coefficients (coefficient B), standardised beta weights (Beta) and values of significance are given for the covariates that reached significance at p<0.01.

suitable assessment tools for factors related to this stress is important for designing interventions to reduce its occurrence. The DAD scale is an appropriate tool as it correlates with caregiver stress better than the BI, and is independent of the GDS and NPI.

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