



SEVERITY OF NEUROPSYCHIATRIC SYMPTOMS AND RELATED CAREGIVER DISTRESS AND NOT CAREGIVER KNOWLEDGE CONTRIBUTE TO CAREGIVER BURDEN IN MILD TO MODERATE DEMENTIA PATIENTS ATTENDING A TERTIARY MEMORY CLINIC: AN ASIAN EXPERIENCE

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BACKGROUND

- Caregivers of patients with dementia often experience high stress level and caregivers burden especially if there are attendant behavioural problems
- The stress of caregiving may be related to knowledge deficit of the disease process and coping strategies
- The objective of this study is to examine if caregiver knowledge, neuropsychiatric symptoms and caregiver distress contributed to caregiver burden in patients with dementia

METHODS

85 patient-caregiver dyads who came for initial cognitive evaluation in a tertiary Memory Clinic between March 2007 to September 2009 were studied. We included caregivers who met the following inclusion criteria:

- ▶ Caregiver of a newly diagnosed patient with dementia OR informant who is not the caregiver, but spent at least 15 hours per week with the patient with dementia
- ▶ Aged 21 years old or above
- ▶ English or Mandarin-speaking

We excluded:

- ▶ Caregivers of patients with dementia who have previously been diagnosed with dementia or counselled with regards to dementia care
- ▶ Informants who spent fewer than 15 hours per week with the patient with dementia
- ▶ Caregivers of institutionalised patients with dementia

We captured data with regards to patient and caregiver demographics. We administered the **Neuropsychiatric Inventory Questionnaire (NPI-Q)¹**, **Zarit Burden Interview (ZBI)²** and a **Caregiver Knowledge questionnaire** to the caregivers

The **Caregiver Knowledge** questionnaire consisted of 24 questions that looked at the knowledge of general symptoms, treatment and services available for dementia and has been developed specifically for this local study (total score of 24)

We analysed the Caregiver demographics, NPI-Q scores, ZBI score and Caregivers Knowledge score using descriptive analysis. Associations between neuropsychiatric symptoms, ZBI score and caregiver knowledge were performed using Pearson correlation. Statistical significance was taken to be $p < 0.05$

RESULTS

Of the 85 dementia patient-caregiver dyads studied,

- ▶ 47.1% (n=40) of patients had mild dementia and 51.8% (n=44) of patients had moderate dementia by DSM-IIIr criteria
- ▶ Patients had aetiologic diagnosis of Alzheimer's Disease (AD) (n=39), AD with stroke disease (n=24), Vascular Dementia (VD) (n=18) and Mixed Dementia (n=3).
- ▶ The caregivers were mainly female (65.9%) (n=56), most were the principal caregiver (95.3%) (n=81), most lived with the patient with dementia (85.9%) (n=73), being either the spouse or children of the patient with dementia, and spent a mean average of 56.9 hours per week with patient

Neuropsychiatric symptoms

- ▶ The most common neuropsychiatric symptoms include sleep/ nighttime behaviour disorder, irritability/ lability, agitation/ aggression, depression and anxiety
- ▶ Neuropsychiatric symptoms for patients is shown in the Table 1 with the mean NPI severity score and NPI caregiver distress score displayed in Table 2
- ▶ The neuropsychiatric symptom with the **highest symptom severity** was 'Aberrant motor behaviour', although this did not cause the most caregiver distress
- ▶ The neuropsychiatric symptom which resulted in the **greatest caregiver distress** was 'Disinhibition', followed by agitation/ aggression, even though these symptoms were only moderate in terms of severity
- ▶ Comparing the mild and moderate groups delusion (12.5% vs 38.6%), hallucinations (7.5% vs 27.3%) and disinhibition (15% vs 34.1%) occurred more frequently in moderate group than in the mild group with $p < 0.05$. (See Table 2)

Zarit caregiver burden

- ▶ The mean ZBI score of the caregivers were 25.34 (± 13.65) which indicated mild caregiver burden. Previous published research findings have suggested that a cut off score ranging from 24-26 has significant predictive validity for identifying caregivers at risk for depression³.

Caregiver knowledge

- ▶ The mean total knowledge score of the caregivers was 71.2% (± 11.79). The items which were most frequently incorrect included:-
 - (1) Rotating care of the patient with dementia among the children is a good arrangement - 67.1% incorrect
 - (2) Dementia is caused by lack of activity - 64.7% incorrect
 - (3) Dementia is part of normal ageing - 62.4% incorrect
 - (4) People with dementia only have memory problems - 51.8% incorrect

Correlation

The total knowledge score on the Caregivers Knowledge Questionnaire was not significantly correlated with the ZBI total score ($r=0.02$, $p=0.86$), NPI total severity score ($r=0.06$, $p=0.61$) and NPI total caregiver distress score ($r=0.02$, $p=0.84$)

Significant correlations were found between **ZBI score and NPI total caregiver distress score** ($r=0.53$, $p < 0.01$) and **ZBI score and NPI total severity score** ($r=0.39$, $p < 0.01$)

There were significant correlations observed in ZBI between NPI severity and caregiver distress in the specific domains of irritability/ lability ($r = 0.58$, $r = 0.69$), apathy ($r=0.45$, $r = 0.65$) and depression ($r = 0.41$, $r = 0.59$) with $p < 0.05$

Table 1. Neuropsychiatric symptoms using NPI

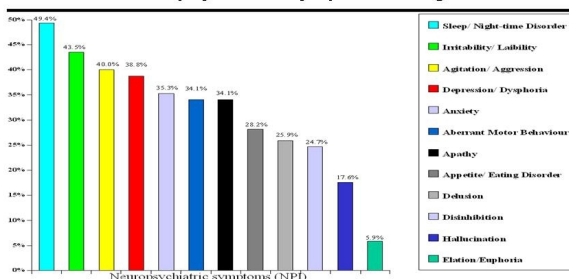


Table 2. Mean NPI severity score and caregiver distress score

Neuropsychiatric symptoms NPI	Total n=85 (%)	Mild Dementia	Moderate Dementia	NPI severity, mean SD	NPI caregiver distress, mean SD
Delusion	22 (25.9%)	5 (12.5%)	17 (38.6%) *	2.09 ± 0.75	2.0 ± 1.63
Hallucination	15 (17.6%)	3 (7.5%)	12 (27.3%) *	2.13 ± 0.83	2.05 ± 1.88
Agitation/Aggression	34 (40%)	15 (37.5%)	18 (40.9%)	1.88 ± 0.77	2.56 ± 1.54
Depression/Dyphoria	33 (38.8%)	13 (32.5%)	20 (45.5%)	1.97 ± 0.77	2.53 ± 1.46
Anxiety	30 (35.3%)	12 (30%)	18 (40.9%)	2.1 ± 0.76	2.07 ± 1.55
Elation/Euphoria	5 (5.9%)	1 (2.5%)	4 (9.1%)	1.6 ± 0.89	1.83 ± 2.23
Apathy	29 (34.1%)	13 (32.5%)	15 (34.9%)	1.79 ± 0.82	2.14 ± 1.75
Disinhibition	21 (24.7%)	6 (15%)	15 (34.1%) *	2.0 ± 0.77	2.71 ± 1.52
Irritability/lability	37 (43.5%)	13 (32.5%)	23 (52.3%)	2.08 ± 0.86	2.43 ± 1.77
Aberrant motor behaviour	29 (34.1%)	12 (30%)	17 (38.6%)	2.31 ± 0.76	2.03 ± 1.57
Sleep/nighttime disorder	42 (49.4%)	17 (42.5%)	24 (53.8%)	2.02 ± 0.78	2.05 ± 1.70
Appetite/eating disorder	24 (28.2%)	10 (25%)	13 (29.2%)	2.21 ± 0.88	2.21 ± 1.84

Severity of the symptom: 1 = Mild 2 = Moderate 3 = Severe
Distress of the symptom: 0 = Not distressing at all 1 = Minimal 2 = Mild 3 = Moderate 4 = Severe
* $p < 0.05$

CONCLUSION

- Our study showed that the common neuropsychiatric symptoms in mild to moderate dementia outpatients were sleep/nighttime behaviour, irritability/lability, agitation/aggression depression and anxiety.
- Of the neuropsychiatric symptoms, disinhibition resulted in the greatest caregiver distress
- Caregiver burden was related to severity of neuropsychiatric symptoms specifically in the domains of irritability/ lability, apathy and depression and resultant caregiver distress
- This is further evidence for need for good behaviour management when targeting caregiver burden in patients with dementia