



Impact of a nurse education and counselling programme on knowledge, attitude, neuropsychiatric symptoms, and caregiver burden: An Asian perspective

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BACKGROUND

- Caring for persons with dementia is demanding and caregivers often experience stress and burden in the caregiving process¹
- Caregivers stress may be caused by lack of knowledge regarding illness process and coping skills in managing behavioural and psychological symptoms of dementia (BPSD)
- Providing caregivers with education and relevant coping strategies are essential in helping caregivers to cope better
- This study aims to look at the impact of a nurse education and counselling programme in the outcomes of i) knowledge, ii) attitude, iii) distress from BPSD symptoms and iv) burden among caregivers of persons with dementia (PWD)

METHODS

- We prospectively recruited 35 caregivers of persons with newly diagnosed dementia who attended our Memory Clinic between March 2007 to September 2009.

We included caregivers who met the following criteria:

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

We excluded:

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

- Information on PWD and caregiver demographics were collected.
- All caregivers underwent a 1 hour individually tailored to the specific patient caregiver education and counselling programme conducted by a nurse clinician with regards to:

- Disease progression
- Information on home safety and legal issues
- Coping strategies for activities of daily living
- Suggestions on non-pharmacological intervention to BPSD
- Advice on activities and mental stimulation for the PWD
- Managing caregivers stress
- Information on community services available for the PWD and caregivers

- **Caregiver Knowledge and Attitude questionnaire, Neuropsychiatric Inventory Questionnaire (NPI-Q)² and Zarit Burden Interview (ZBI)³** were administered to the caregivers at the initial visit and 3 months post counselling.
- The **Caregiver Knowledge and Attitude questionnaire** has been developed specifically for this local study.
- The questionnaire consisted of 34 items, comprising 24 items that assessed knowledge of general symptoms, treatment and services available for dementia (shown in table 1), and 10 items that examined the attitudes of caregivers towards dementia and the caregiving process using a 5- point Likert scale.
- We analysed caregiver demographics, caregivers knowledge scores, NPI-Q scores and ZBI scores using descriptive analysis. We compared the pre- and post-intervention scores for caregiver knowledge, NPI-Q and ZBI using paired sample t- test. Statistical significant was taken to be $p < 0.05$

Table 1
Caregiver Knowledge Questionnaires

Q1 Dementia is a disease of the brain
Q2 Dementia is caused by lack of activity
Q3 Dementia is a part of normal aging
Q4 The most common type of dementia is Alzheimer's disease
Q5 Alzheimer's disease is caused by changes in the nerve cells of the brain
Q6 Vascular dementia refers to dementia caused by stroke
Q7 Dementia is a stable illness that does not progress with time
Q8 People with dementia have no feelings and react less to other people
Q9 People with dementia only have memory problems
Q10 Memory loss and forgetfulness in people with dementia will progressively get worse as time goes by
Q11 Language problem or word finding difficulty is a symptom of dementia
Q12 Having false belief that others are trying to harm him/her is one of the behavioural problem in dementia
Q13 Behaviour change is NOT a sign and symptom of dementia
Q14 People with dementia can sometimes see or hear things that are not real
Q15 Leaving a person with dementia home alone is unsafe as they are at higher risk of fall and injuries
Q16 Dementia can be cured
Q17 The purpose of memory medications used to treat dementia is to cure dementia
Q18 Mental stimulation is important for people with dementia, as this will help to prevent boredom and behaviour problem
Q19 People with dementia will be less confused if their activities of daily living are structured in a routine
Q20 There is no need to help people with early dementia plan ahead for their financial affairs as they still have the capability to manage these affairs until the advanced stage.
Q21 Dementia patients are best managed in nursing homes where they are looked after by healthcare professionals
Q22 Rotating care of the demented patient among the children is a good arrangement of care
Q23 In Singapore, there are currently specific daycare centres for people with dementia
Q24 In Singapore, there is no support group for caregivers of patients with dementia

RESULTS

Respondent Profile

Of the 35 caregivers of PWD studied,

- 91.4% (n=32) were the primary caregiver living together with the PWD and spent a mean of 60.4 (+44.2) contact hours/week with the PWD
- Relationship to PWD: The majority were adult children 71.4% (n=25), followed by spouses 22.9% (n=8).
- Majority were: female 74.3% (n=26), Chinese 88.6% (n=31), aged between 41-60 years old 62.9% (n=22), not working 51.5% (n=18) and of at least tertiary education level 82.9% (n=29)

Caregiver Knowledge (Figure 1) and Attitude

- Post counselling, the mean total knowledge scores increased significantly by 9% from 74.2% (+10.6) to 83.2% (+10.2) [$p < 0.01$].
- When analyzed by knowledge domains, a non significant trend towards improvement in the domains of disease knowledge (Q1,3,4,5,6,8,9,11,12,13,14), progression (Q10), treatment (Q16,17), management (Q15,20,22) availability of dementia day care (Q23) and support group for caregivers of PWD (Q24) were observed.
- There was no significant difference observed in caregiver attitude towards dementia pre and post counselling.

Neuropsychiatric symptoms (Figure 2)

- There was no significant difference in the mean NPI total scores (NPS), mean NPI total severity scores and mean NPI total caregiver distress scores pre and post counselling.
- There were trends toward decreased caregiver distress related to NP symptoms in the specific domains of sleep/nighttime behaviour, aberrant motor behaviour, irritability/lability, disinhibition, apathy, elation and hallucinations, although appetite /eating disturbance caused increased distress.

Zarit caregiver burden

- The mean ZBI score pre-counselling was 24.3 (+13.9). This reflects a significant level of caregiver burden at baseline that has been shown from previous research to be predictive of increased risk of caregiver depression.⁴
- Post-counselling, the mean ZBI score increased slightly to 25.6 (+13) (NS), which indicated that the intervention was not effective in reducing caregiver burden within the duration of the study period.

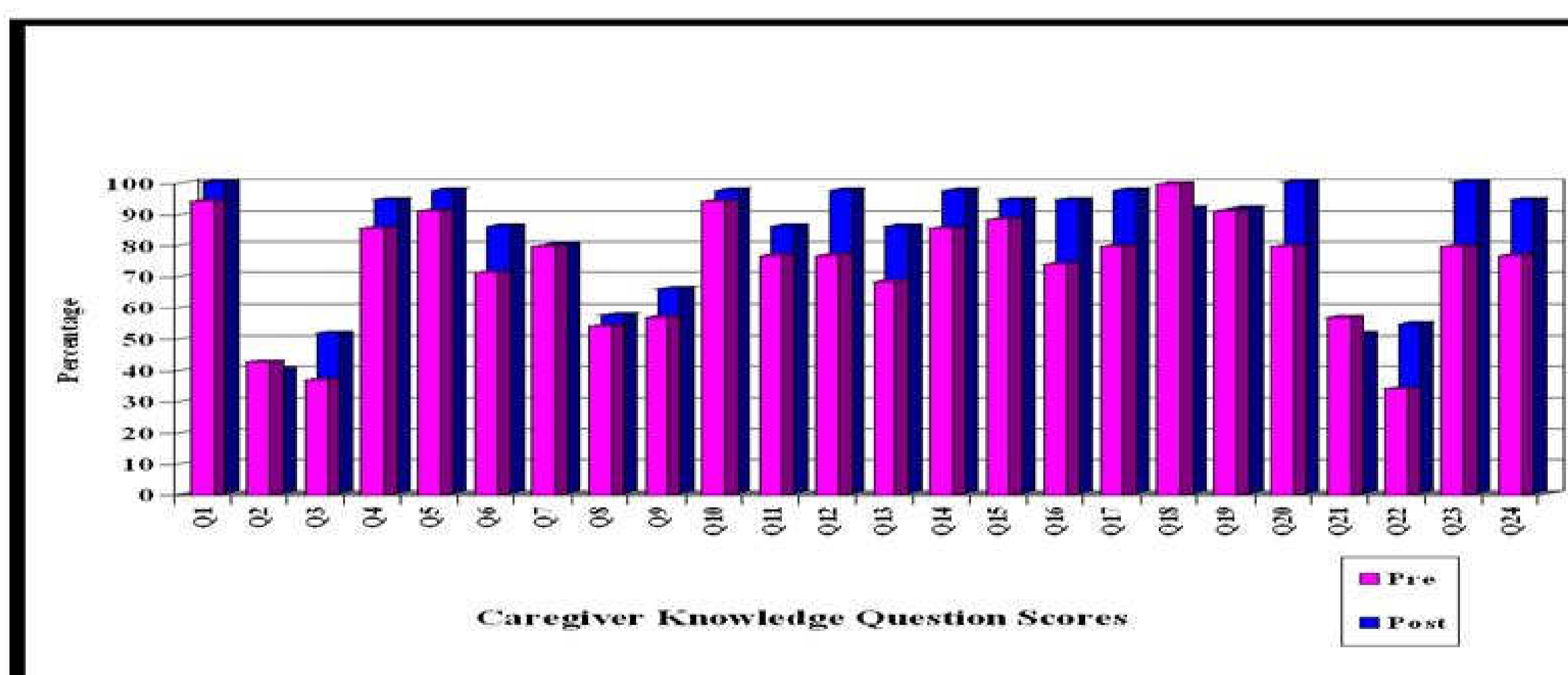


Figure 1

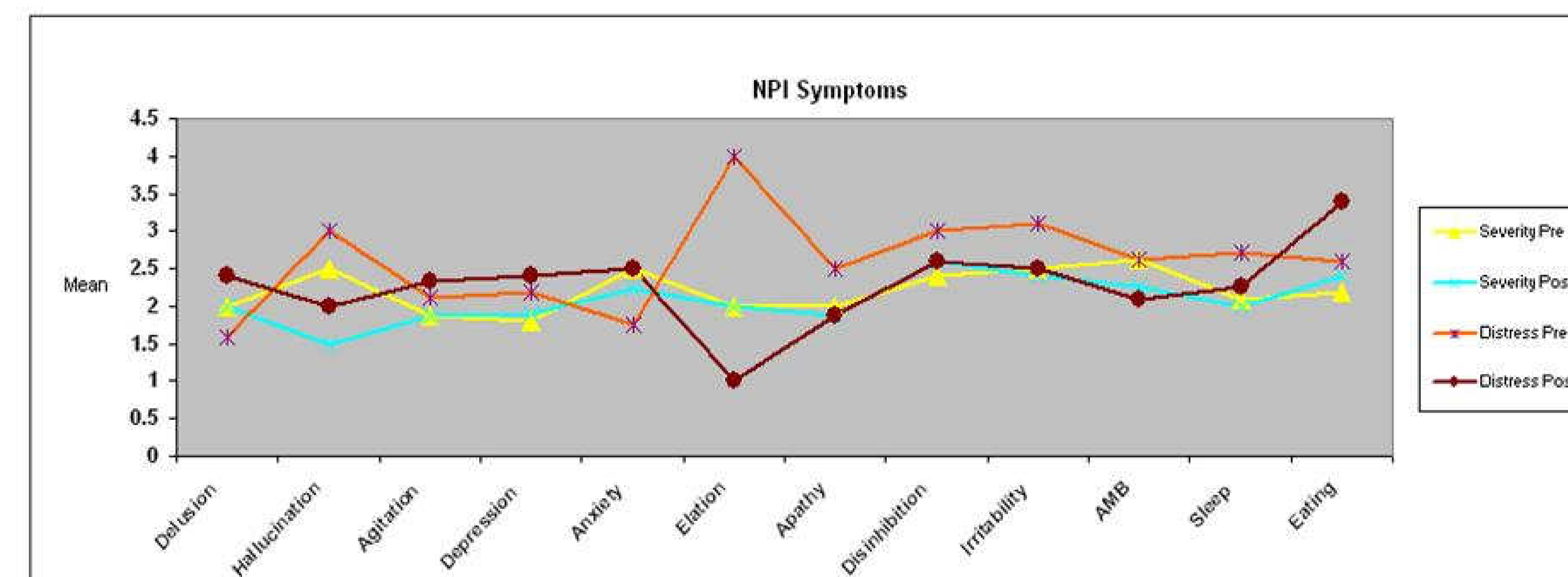


Figure 2

CONCLUSION

- We conclude that our nurse-led education programme was effective in improving caregiver knowledge and possibly some aspects of caregiver distress from the NP symptoms among caregivers who had a significant degree of caregiver burden at baseline.
- The lack of follow-up sessions and short study duration 3 months may have limited its usefulness in improving caregiver attitude and burden.
- Future studies involving a more sustained caregiver education and support programme with a longer study period may yield clearer benefits.