Introduction

Patients suffering from dementia often have neuropsychiatric disturbance accompanying the cognitive deficits. These include, mood disturbance, psychotic symptoms, aggression, activity disturbance, vegetative symptoms like sleep and appetite change. This behavioral and psychological paradigm was a relatively neglected area in dementia research until the recent decade. Many experts and international bodies (e.g. the International Psychogeriatric Association) have now acknowledged their significance and engaged in a broad spectrum of studies, hoping to improve our knowledge and understanding of these common and distressing symptoms in demented patients.

The common occurrence of neuropsychiatric disturbances in dementia is one of the many reasons why they deserve more detail researches. Unlike the cognitive deficits, many neuropsychiatric disturbances, e.g., psychotic and affective symptoms are potentially remediable. Their significance were also demonstrated by various studies that they contributed to the caregiver's burden [18,38,39] , and were the major cause of institutionalization for dementia patients.[19-21,53] Some noncognitive disturbances are of prognostic significance, e.g., delusion was found to predict faster intellectual decline in AD.[11-12,14-16,58] and that the presence of depression with Alzheimer dementia was shown to be associated with poorer prognosis with increased mortality rate reported in earlier follow-up studies.[47,48] Moreover, there are reports of possible neurochemical, neuropathological [7-9,57] correlates for the non-cognitive disturbances in AD. For example, Zweig et al (1996)[9] and Zubenko et al (1988)[57] demonstrated neuropathologically that AD patient with depression showed a greater loss of aminergic neurones in the locus coeruleus, dorsal raphe nucleus and substantial nigra than those without depression. These findings allow us to identify subgroups of AD which may show different response to treatments and clinical course.

Caregiver distress

Caregivers' burden is reported to be a critical determinant of negative caregiving outcome. It is an important factor that predicts institutionalization for demented subjects.[37,42] Caregiver's burden is related not just to the practical aspect of caregiving, the emotional burden secondary to the caregiving and the behavioral disturbances of the patients are equally straining. Informal caregivers of demented elderly were observed more likely to be depressed than those nursing normal/physically debilitated elderly [17,59] and studies revealed that neuropsychiatric impairments, instead of functional loss or the severity of dementia were more influential for caregiver's burden.[37, 46]

Purpose of the study

Most of the studies of non-cognitive disturbances in the literature are from western countries and reports involving Chinese community are scarce. One of the reasons is the lack of assessment tools. In Hong Kong, the only validated instrument available is the Chinese version of the Rating Scale for Aggressive Behavior in the Elderly (CRAGE).[84] The local validation of the Chinese version of BEHAVE-AD has just been completed and awaits publication. The information concerning the neuropsychiatric disturbances of our demented population will remain unclear to us unless more instruments can be developed to facilitate researches.

The current project of translating the Neuropsychiatric Inventory (NPI)[3-4] into Chinese is the initial step of a collaborative study with his research group to compare the neuropsychiatric profile of demented patients as well as the characteristics of caregivers between the two localities. The first part of this study is to assess the validity and applicability of the inventory in our demented subjects while the second part aims to study the period prevalence of the non-cognitive disturbances in our demented out-patient sample. This will be one of the earliest data reported in Hong Kong and can provide important clinical information for reference.

Structure and scoring of the instrument

One of the merits of NPI is its comprehensiveness. It can be used to assess a wide range of behavioral disturbances in dementia patients. It is a structured interview with the caregiver who is familiar with the patient. Twelve types of neuropsychiatric abnormalities are assessed which include delusions, hallucinations, agitation, depression/dysphoria, anxiety, euphoria, apathy, disinhibition, irritability/lability, aberrant motor behavior, night-time behavior, appetite/eating change. Another advantage of the instrument is that it requires only an average of 15 minutes to complete the evaluation which is accomplished by the development of screening questions for each specific behavioral domain.

The caregiver is asked to rate the problem behavior that has occurred in the past one month and which was not present before the onset of dementing illness. The time frame can be adjusted according to the need of the assessment, such as psychopathology before and after drug treatment. Under each behavioral domain, a screening question is first asked. If the response is negative, the assessor can proceed to ask the stem question of the next behavioral disturbance. If the response to the screening question is positive, it is followed by asking the subquestions in order to delineate the extent of the problem behavior. After administration of the subquestions, the caregivers will rate the frequency and the severity of the abnormality. Rating both the frequency and severity of behavioral

changes is potentially useful in assessing interventions that may affect only one of these dimensions and allow a more refined analysis of the treatment effect.

Caregiver distress associated with this neuropsychiatric disturbance was assessed by a six-point scale from 0 (no distress) to 5 (very severe or extreme distress).

The composite score of each behavioral domain is given by multiplying the frequency with the severity. The 12 composite scores can be added to give a total score. A total distress score can also be calculated from adding the distress scores of all the items.

The reported content validity, concurrent validity, internal consistency reliability, item independence, inter-rater reliability, and test-retest reliability of the original English version were satisfactory.[5]

Method

The NPI was first translated into Chinese by 2 bilingual psychiatrists and then back translated into English by an independent bilingual psychiatrist. The Chinese version (CNPI) was modified until the back-translated version was comparable with the original English version. It was then tested for its acceptability in a pilot sample of outpatient dementia patients before utilizing in the study samples. The first part of the project was to determine the reliability and validity of the CNPI and we then proceeded to analysis the behavioral profile of our out-patients with the instrument.

Subject

For the validation study, a mixed sample of 62 new and old cases of community-dwelling demented subjects were selected from the psychiatric out-patient clinic of the Chinese University. Among these 62 subjects, 46 were consecutive new referrals to the clinic and these new cases were chosen for the part II study. Diagnosis of Alzheimer's disease was based on NINCDS/ADRDA[25] criteria of probable Alzheimer's Disease while diagnosis of vascular dementia was made according to DSMIV criteria. Most of the patients had received laboratory tests including complete blood picture, thyroid function test, liver and renal function test and serology to exclude syphilis. CT scans were done in subjects when appropriate and feasible. A group of 29 normal subjects were recruited from the community as controls. Written consent was obtained from the subjects and caregivers. If the demented patients were not capable of consenting whom did not show any sign of refusing to the research, they were included into the study with the consent of the caregivers.

Assessment

All demented and normal subjects were assessed by attending psychiatrists and the demographic data collected. The caregivers of the demented subjects were interviewed by the author and trainee psychiatrists with the Chinese version of BEHAVE-AD concerning the behavioral disturbance in the preceding four weeks. The patients' Chinese Mini-Mental State Examination (CMMSE)[27], the Functional Assessment Staging (FAST)[28] of dementia and the Chinese Hamiltion Rating Scale of Depression (CHDS)[29-31] were also completed. A research assistance or an independent psychiatrist who was blind to the rating of BEHAVE-AD, interviewed the caregiver with the Chinese Neuropsychiatric Inventory (CNPI), again for behavioral disturbance of the preceding four weeks. Both the screening questions and all subquestions were asked in all the demented subjects irrespective of the answer to the screening questions. This is done in order to calculate the false negative rate of the screening questions. The caregivers of normal control were interviewed with the CNPI while all normal subjects had the CMMSE performed.

Validity and reliability of CNPI

The CNPI was tested for its *concurrent validity* by calculating the Spearman correlation coefficients between the NPI subscales with the appropriate subscales of the BEHAVE-AD and CHDS. Cronbach's coefficient alpha was calculated to assess the *internal consistency* reliability of the instrument. A subgroup of 29 patients' caregivers were interviewed to determine the *inter-rater reliability* by having 2 raters score the CNPI response of an interview conducted by one of the raters. Each rater was blind to the rating chosen by the other. *Screening question sensitivity* was also calculated from the false negative rate detected by a positive answer from the subquestions but a negative answer from the stem question.

Analysis of data was done by using SPSS version 8.0. Non-parametric method were employed for analysis involving CNPI scores as all subscale and global scores identified in the patient groups are not normally distributed. Spearman correlation was used for assessing correlation between CNPI Scores, between CNPI scores and BEHAVE-AD scores/demographic variables (age, educational level and duration of illness)/MMSE scores. Kruskal-Wallis and Mann-Whitney U was used to assess between group differences in CNPI scores while between group differences for normally distributed data like MMSE and age has employed independent sample t-test.