Caregiver burden associated with behavioral and psychological symptoms of dementia (BPSD) in Taiwanese elderly

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ABSTRACT

The purpose of this study was to investigate caregiver burden associated with BPSD in Taiwanese people. The study had a cross-sectional design. Eighty-eight patients with dementia and 88 caregivers who visited the memory clinic of a medical center from January 2007 to December 2007 were recruited. The BPSD were assessed using the neuropsychiatric inventory (NPI); caregiver burden was evaluated using the NPI caregiver distress scale (NPI-D). Demographic data on the patients and caregivers along with patients' cognitive functions and clinical dementia ratings were collected. In addition to descriptive statistics, we analyzed the relationship between each parameter and caregiver burden using binary correlation. The results showed a statistically significant positive correlation between the total NPI-D score and the total NPI score ($r = 0.898$, $p < 0.001$). For individual BPSD, delusions had the highest mean NPI-D score, followed by agitation/aggression, anxiety, irritability/lability, and dysphoria/depression. The symptom frequency of anxiety, delusions, and agitation/aggression showed a statistically significant positive correlation with caregiver's NPI-D score. These findings suggest that improvement of treatments for delusions, agitation/aggression, anxiety, irritability/lability, and dysphoria/depression among dementia patients may reduce caregiver burden.

1. Introduction

According to statistical information from the Authorites of Taiwan, by the end of 2009 people aged 65 years and older numbered 2.46 million, or 10.6% of Taiwan's total population (Ministry of Interior, Taiwan, 2010). The prevalence of dementia in people aged 65 years and older in Taiwan is 2–3.7% (Liu et al., 1995; Lin et al., 1998); therefore, the estimated number of people with dementia is 50,000–100,000. In Taiwan, approximately 80% of the care of dementia patients is provided in the community by family members, a percentage similar to that in Western countries (Haley, 1997; Fuh et al., 1999). Fuh et al. (1999) reported that over half (56.6%) of main caregivers of people with dementia in Taiwan

spend more than 8 h per day on caregiving. Among the factors associated with caregiver distress, the patient's BPSD are most closely associated with caregiver burden (Meiland et al., 2005; Onishi et al., 2005; Lim et al., 2008). Regarding individual BPSD, Kaufer et al. (1998) reported that irritability/lability resulted in the highest burden, and that there were also strong associations between burden and agitation/aggression, dysphoria/depression, delusions, and hallucinations. A Japanese study (Matsumoto et al., 2007) indicated that agitation/aggression was associated with the highest caregiver distress and that agitation/aggression, delusions, apathy/indifference, irritability/lability, and aberrant motor behavior showed statistically significant correlations with burden.

Although it is important to study the association between caregiver burden and individual BPSD, articles mentioning this topic are still rare in Taiwan. The aim of this study was to investigate caregiver burden associated with individual BPSD in Taiwanese people with dementia. The association between caregiver burden and patient and caregiver demographics was also examined.

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2. Subjects and methods

2.1. Subjects and study design

This study had a cross-sectional design. The diagnostic criteria for dementia syndrome were established according to the DSM-IV (APA, 1994). Eighty-eight patients with dementia and 88 caregivers who visited the memory clinic of a medical center in central Taiwan from January 2007 to December 2007 were recruited. The inclusion criteria for caregivers were as follows: (1) being a relative of the patient, with an age older than 18 years; (2) serving as primary caregiver and having an intimate knowledge of the patient developed over time; and (3) agreement to be interviewed.

This study was approved by the institutional review board of the medical center.

2.2. Assessment for dementia

The patients' BPSD were assessed using the NPI (Cummings et al., 1994; Cummings, 1997), administered through a structured interview with a caregiver who was familiar with the patient. The NPI was developed to assess psychopathology in dementia patients. It evaluates 12 behavioral and psychological symptoms that are common in dementia: delusions, hallucinations, agitation/aggression, dysphoria/depression, anxiety, euphoria/elation, apathy/indifference, disinhibition, irritability/lability, aberrant motor behavior, nighttime behavioral disturbances, and appetite and eating abnormalities. A screening question was asked first, followed by sub-questions, if the response to the screening question suggested the presence of neuropsychiatric abnormalities. After administration of the sub-questions, the caregiver rated the frequency and severity of each symptom or behavior, using scores from 1 to 4 for frequency and scores of 1–3 for severity. The NPI score for each BPSD was the product of the frequency and severity subscores (frequency multiplied by the severity). The total possible NPI score ranged from 0 to 144.

We also assessed patients' performance of activities of daily living (ADL) with the Barthel index (BI) (Collin et al., 1988), instrumental ADLs with the IADL scale (Lawton and Brody, 1969), clinical dementia stage with the clinical dementia rating scale (CDR) (Hughes et al., 1982), and cognitive function with the Chinese version of the cognitive abilities screening instrument (CASI, C-2.0) (Lin et al., 2002). The CASI (Teng et al., 1994) is a globally recognized method of measuring cognition that has been used in a number of international studies of dementia. It includes items similar or identical to those used in the mini-mental state examination (MMSE) (Folstein et al., 1975), the modified MMSE (Teng and Chui, 1987), and the Hasegawa dementia screening scale (Hasegawa, 1983). The Chinese version of the CASI consists of nine domains: long-term memory, short-term memory, attention, concentration, orientation, abstraction and judgment, language abilities, visual construction, and category fluency. It can be administered in 15–20 min. Its total possible score ranges from 0 to 100. Applying the test to a predominantly illiterate elderly Chinese population, a cutoff score of 50/51 for dementia was reported, with sensitivity of 0.88 and specificity of 0.94. The instrument's cutoff scores according to different educational levels were also calculated and showed good sensitivity and specificity (Lin et al., 2002). The MMSE score in this study was derived from part of the CASI score.

2.3. Assessment of family caregivers

Caregiver burden was evaluated using the NPI-D (Kaufer et al., 1998). This is an adjunct scale to the NPI for assessing the impact of BPSD on caregiver distress. After rating each symptom domain of the NPI, caregivers were asked to rate their emotional or psychological distress on a scale from 0 (not at all distressing) to 5 (extremely distressing). The NPI-D has a moderate correlation ($r = 0.51$, $p < 0.01$) with the Zarit caregiver burden inventory (ZBI) (Zarit et al., 1980) and has high inter-rater ($r = 0.96$) and test–retest ($r = 0.92$) reliability ($p < 0.001$) (Cummings et al., 1994). The internal consistency in this study was high (Cronbach $\alpha = 0.84$).

We also assessed caregiver depression using the Center for Epidemiologic Studies depression scale (CES-D) (Radloff, 1977). Higher scores (16 or above) indicate that the person is "at risk" of depression or in need of treatment.

2.4. Statistical analyses

Data entry and analysis were performed using SPSS for Windows, version 10.0 (SPSS Inc., Chicago, IL, USA). In addition to descriptive statistics, the relationship between dementia patients' demographics and caregiver burden as well as caregivers' demographics and caregiver burden were tested using the Pearson correlation. Subsequently, we analyzed the frequency, severity, and product of frequency and severity of individual BPSD and their emotional impact on caregivers (NPI-D) using the Pearson correlation. For all analyses, the probability level considered to indicate statistical significance was set at $p < 0.05$.

3. Results

3.1. Demographics of dementia patients

Of the 88 patients with dementia, 64.8% were female, and 48.9% were between 75 and 84 years old, with a mean age of 80.0 ± 7.7 years ($\pm$S.D.). Almost half of them (46.6%) were illiterate. Most of them (94.3%) lived with their families. In terms of ADL, 85 of the dementia patients (96.6%) were impaired in one or more IADLs, and 36 of them (40.9%) were impaired in one or more ADLs. The mean CASI score of the patients was 45.1 ± 23.3, the mean MMSE score was 13.8 ± 6.5, and the predominant clinical stage of dementia was mild dementia (CDR = 1) (Table 1).

3.2. Demographics of caregivers

Of the 88 caregivers, 62.5% were between 40 and 64 years old, with a mean age of 54.6 ± 14.1 years; 52.3% were female; the most common caregiver relationship to the dementia patient was child (45.5%); and 51.1% had an educational level of high school or higher. The mean total NPI-D score of the caregivers was 8.8 ± 10.9 (range, 0–43), and 42% of the caregivers had a CES-D score of 16 or greater (Table 1).

3.3. Correlation between demographics and caregiver burden

Table 2 shows the correlation between demographics of patients and caregiver burden. Patients' living with their families had a statistically significant correlation with caregiver burden ($t = -3.688$, $p = 0.003$). Moreover, poorer performance of IADL and ADL, lower CASI and MMSE scores, higher CDR, and higher NPI scores had statistically significant positive correlations with caregiver burden.

Table 3 shows the correlation between demographics of caregivers and caregiver burden. Being married had a statistically significant positive correlation with caregiver burden ($t = -3.587$, $p = 0.002$).

3.4. Relationship between individual BPSD and caregiver distress

Table 4 shows the correlation between individual BPSD and caregiver distress. The total NPI-D score had a statistically