



Development of a burden scale for caregivers of dementia patients



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ABSTRACT

Objective: To develop a scale to measure the burden of care for caregivers of patients with dementia and explore its factor structure.

Methods: The initial draft of the Thai dementia patients' caregiver burden (Thai-DCAB) scale was developed based on literature review, in-depth interviews and expert opinions. The drafted scale was administered to 203 caregivers of dementia patients treated at two large public hospitals in southern Thailand. An exploratory factor analysis using maximum likelihood extraction with varimax rotation was conducted. The reliability of the scale was assessed using Cronbach's alpha.

Results: The Thai-DCAB scale consisted of 18 questions. Three factors were obtained, covering psychological, physical and financial burdens of the caregivers in taking care of dementia patients. These three factors accounted for 67% of the variance. The Cronbach's alpha coefficient was 0.95.

Conclusion: The Thai-DCAB scale has high internal consistency and captures key theoretical constructs of the perceived burden among caregivers of patients with chronic and deteriorating dementia and in accordance with the social and cultural contexts and the way of life of the Thai people.

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1. Introduction

The change in the age structure of the population in the world has resulted in an increasing proportion of elderly people. Asia is one of the regions where many countries will face population aging in the near future. By 2050 it is expected that in many countries in the region more than 40% of the population cohort will be over 60 years of age and the median age will approach 40 years (United Nations, 2002). Asia had more than half (55%) of the world's older people in 2012 (United Nations, 2012). Population aging influences family composition and living arrangements, and the need for health-care services. The health of older persons typically deteriorates with increasing age, inducing greater demand for long-term care as the number of older people increases.

Dementia is one of the consequences of a rapid increase in the aging population worldwide. It is estimated that nearly 35.6 million people worldwide live with dementia, with the number being projected to almost double by 2030 and more than triple by 2050. About 58% of dementia patients live in low- and

middle-income countries and it is likely to rise to more than 70% by 2050 (World Health Organization and Alzheimer's Disease International, 2012). The population of Thailand is progressively aging. The proportion of older persons will increase to 14% in 2015, 20% in 2025 and nearly 30% by 2050 (United Nations Population Fund, 2006). In parallel, the prevalence of illnesses and diseases among the elderly will increase, including the prevalence of dementia, which increases with age.

Dementia is devastating not only for the people who have it, but also for their caregivers and families. Aside from impairment of memory, thinking process, and cognitive function, 78% of patients with dementia also have co-existing behavioral, mental and emotional symptoms (Seitz et al., 2010). This prevalence is especially high among those with Alzheimer's disease (Burns and Iliffe, 2009). Several studies have found that caregivers of dementia patients are faced with a high burden because of its extremely high cost of care and high need of dependency (Varela et al., 2011; Nunnemann et al., 2012; Wang, 2012). These can affect the interaction and relationship between family members, resulting in an increasing risk of mental disorders, such as depression, anxiety, sleep problems and stress, and a low quality of life among the caretakers (Serrano-Aguilar et al., 2006; Papatavrou et al., 2007, 2011; Varela et al., 2011).

Several tools have been developed and used widely for measuring the caregivers' burden for patients with chronic diseases and dementia such as the Zarit Burden Interview,

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Caregiver Self-assessment Questionnaire, Brief Measures of Secondary Role and Intrapsychic Strains (American Psychological Association, 2013; Van Durme et al., 2012). These tools include items pertaining to the effects on the caregivers in term of emotional and mental health, physical health, employment, available personal time, family and social relations, feelings toward the patient, feeling of uncertainty and financial burden. However, these tools were developed based on a western culture. Asian societies differ from western societies mainly regarding the family bond and in the caring for elderly family members. Caring for one's parents is considered a duty and a way to express one's filial piety. In western societies, healthcare personnel are usually the main caregivers for the elderly while in Thai society, the family members or relatives play the major role as primary caregivers (Songkhla Rajanagarindra Psychiatric Hospital, 2012).

As each country setting has its own unique context, the development of an assessment tool that suits the contexts of the Thai society is necessary. However, a measuring instrument on the burden of care in the Thai language is available only for chronic physical diseases and it was translated from English (Toonsiri and Sansern, 2011). This study thus aimed to develop an instrument – the Thai dementia patients' caregiver burden (Thai-DCAB) scale to measure the burden of care of dementia patients on their caregivers. Such an instrument could provide clinically useful assessment information for health workers to identify caregivers with a high level of burden and make appropriate plans for the treatment and care of both the patients and their relatives. The current paper reports the development process and structure of this newly developed tool.

2. Materials and methods

2.1. Subjects

Caregivers of dementia patients who received treatment at the Songkhla Rajanakarindra Psychiatric Hospital or Surajthanee Regional Hospital during November 2011 to April 2012 were invited to participate in the study. Of 246 patients approached, 203 agreed to participate, giving a response rate of 82.5%.

2.2. Materials

To prepare the initial draft of the scale, we reviewed the literature related to burdens of caregivers of patients with chronic diseases and dementia. In-depth interviews were then performed with nine caregivers of dementia patients and three mental health personnel who specialized in dementia care. Six sub-themes were derived from the literature review and in-depth interviews, including caregivers' physical, mental and emotional health; availability of time for personal, family and social needs; financial burden; ability to provide care; accessibility to healthcare and social resources; and perception of participation of family members in terms of care-giving and their financial contribution. Under these sub-themes, an initial list of 20 items was initially developed. The first draft of the scale was reviewed by a panel of experts, including a psychiatrist, a neurologist, three psychiatric nurses, a clinical psychologist, an assessment specialist, a social worker, and three relatives or caregivers of dementia patients with five or more years of experience in providing care. The draft was then modified and reviewed again by four experts experienced in working with elderly patients with chronic medical and psychiatric conditions and/or dementia, including a clinical psychologist, a geriatric nurse, a psychiatric nurse and an assessment specialist, for its wording and face validity.

The scale was then pilot tested on 43 caregivers of patients with dementia at the study psychiatric hospital. The purpose of this

pilot test was to check the comprehensibility and wording of the scale, as well as time spent in completing the scale, thus a sample size of 43 caregivers was considered adequate. Some minor modifications of the wording were then made to improve the clarity. The final draft consisted of 20 questions. Each item was rated on a 5-point Likert scale, none, a little, moderate, a lot and greatest.

It was hypothesized that a caregiver who took care of a dementia patient with severe behavioral and psychological symptoms would have a higher perceived burden. In order to examine this relationship, the Thai version of the Neuropsychiatric Inventory Questionnaire (NPI-Q-Thai) was administered to 43 caregivers. The NPI-Q-Thai is a questionnaire used to measure the patients' behavior and psychological symptoms of dementia by asking the caregiver to rate the severity of the patient's symptoms. It has been validated and used widely in clinical settings in Thailand (Hemrungronj, 2011). There are 12 items: symptoms of delusion, hallucination, agitation and aggression, depression, anxiety, euphoria, apathy, disinhibition, irritability, aberrant motor behavior, difficulty sleeping, and eating problem.

2.3. Procedure

Institutional ethical approval was obtained from Songkhla Rajanakarindra Psychiatric Hospital and Surajthanee Regional Hospital. All care-givers were fully informed about the purpose of the study and the procedure and gave their consent to participate. A face-to-face, structured interview was performed in privacy by a well trained nurse at the study hospitals.

2.4. Data analysis

Demographic data of caregivers were analyzed using descriptive statistics, i.e. frequency and percentage. Exploratory factor analysis with the maximum likelihood and varimax orthogonal rotation techniques was used to extract factor components. The number of components was retained based on the eigenvalues being greater than 1, an elbow in the graph of the scree-test and also on heuristic and practical grounds (Kaiser, 1974). Internal consistency was calculated for each component and the whole scale using Cronbach's alpha coefficient. The overall NPI-Q-Thai score was calculated by summing the scores of 12 items and then categorized into tertiles. The relationship between the level of burden assessed by the Thai-DCAB scale and the caregivers' perception of the severity of the patient's symptoms was analyzed using ordinal logistic regression.

3. Results

3.1. Sample characteristics

Altogether, 203 caregivers participated in the study. Most were female (64.5%), married (67.5%) and Buddhist (67.4%). Their average age was 49.13 years (SD = 10.17 years, range = 29–65). More than one-third had bachelor's degree education or higher (37.9%), while the rest achieved vocational (15.3%), secondary (24.1%) or primary school education (22.7%). Similar proportions were engaged in a fulltime job as a civil servant or state enterprise employee (27.6%), business owner and vendor (27.1%), or farmer (25.1%). Their average income was 31821 Thai Baht (1060 US dollars) per month. The highest proportion of caregivers was the patients' children (56%), followed by spouse (33%). The average length of time in caring for the patient was 6.5 years (range = 1–13 years). The average age of dementia patients receiving care was 75.26 years (SD = 7.5 years), with a mean duration of illness being 4.9 years (SD = 3.64). Their average Thai Mini-mental Status

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