



Original Article

Sustained Benefit of a Psycho-educational Training Program for Dementia Caregivers in Taiwan[☆]Chien-Chi Hsu^{1,2}, Yi-Min Wang³, Chiu-Rong Huang⁴, Fang-Ju Sun⁴, Jui-Ping Lin³, Ping-Keung Yip^{3,5,6**}, Shen-Ing Liu^{1,2*}

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SUMMARY

Background: Informal caregivers for dementia are vulnerable to psychological distress. Researches have shown the inconsistent results in the efficacy of various psychosocial interventions for burden of informal caregivers for patients with dementia. The aim of this study was to provide further understanding for the relative efficacy of psychosocial interventions in lessening the burden of caregivers.

Methods: This research was a prospective, longitudinal, one-group pretest–posttest design to measure the effectiveness of 32-h psycho-educational training program for family caregivers in Taiwan. The Chinese version Zarit Burden Interview (ZBI), the 12-item version of General Health Questionnaire (GHQ-12), and Medical Outcome Study 36-item Short-Form Health Survey (SF-36) were assessed at pre-intervention, 3-month post-intervention, 6-month post-intervention, and 9-month post-intervention. Pre–post comparisons were made using general estimate equations (GEE) to confirm the longitudinal effects of the intervention for caregivers.

Results: A total of 53 caregiver–patient dyads met the study criteria, of whom 34 (64.2%) dyads completed total assessments. There were significant improvements of the overall effects on ZBI ($p < 0.001$), GHQ-12 ($p = 0.044$) and mental component summary of SF-36 ($p = 0.008$). No significant improvement was found in physical component summary of SF-36 ($p = 0.091$).

Conclusion: The caregivers for dementia patients may have sustained benefit of reducing burden, decreasing psychological morbidity and enhancing psychological wellbeing after the intensive psycho-educational training programs' intervention.

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1. Introduction

Dementia is primarily recognized as a disease of old age. The prevalence of dementia is estimated 5–7% in most world regions¹. Previous epidemiological studies in Taiwan revealed that 2–4.4% of the community elders suffered from different forms of dementia^{2,3}.

Dementia creates substantial, irreversible cognitive decline, various behavioral psychological disturbances, and later physical disabilities for the elderly. The disability weight for dementia is estimated to be higher for most other health condition, apart from spinal-cord injury and terminal cancer⁴.

Informal, unpaid caregivers provide a great resource for the elderly. Most informal caregivers in home are family members and the corner-stone of support for dementia patients. Taking care of demented elderly is particularly time consuming; many caregivers need to cut back on work. The insufficient training and preparations on caregiving task result in a lot of stress on family caregivers. The low rate of long-term care service use may contribute to the family caregivers' burden⁵. Furthermore, caregivers who interact with the health care system often receive inadequate support from health professionals and frequently feel abandoned and unrecognized by

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the health care system. Several domains including culture, knowledge, social support, psychiatric symptomology and family conflicts have been used to assess the stress of the caregivers⁶. The degree of caregiver stress impacts the patient–caregiver dyads. A number of adverse outcomes for the dementia caregiver, such as psychological, physical and financial burden of the caregiver, directly lead to increases in institutionalization of the person with dementia and declines in quality of life for both the patient and the caregiver.

Various methods of intervention have been reported to alleviate the stress, promote knowledge and techniques of care for family caregivers, but the results and benefits were conflicting^{7–9}. Meta-analysis revealed the importance of different elements of interventions that may affect the result of outcome^{9–11}. Several review studies have noted that psychosocial intervention and education of caregivers have become an important part of recommendation in dementia care^{9,11}. Nevertheless, it has been argued that psychosocial interventions for caregivers have no effect on decreasing their care burden^{10,12–15}.

In Taiwan, few studies investigated the effectiveness of psychosocial interventions for caregivers of people with dementia^{16,17}. In addition, only one study examined the short-term effectiveness of psycho-educational group for caregivers of people with dementia¹⁷. However, there are still many questions about the long-term effects of psycho-educational group on the caregivers' burden, psychological morbidity, and quality of life, so we developed a pilot trial to study the persistent effectiveness of a psycho-educational program for the family caregivers of people with dementia. The program consisted of structural psycho-education and unstructured supportive groups which covered the advantage of information sharing and emotional support. The primary goal of this study was to evaluate whether the program reduced the burden of dementia caregivers. The secondary goals were to assess its effectiveness to reduce psychological distress and enhance quality of life.

2. Methods

2.1. Study design and interventions

This research was a prospective, longitudinal, one-group pretest–posttest design to measure the effectiveness of psycho-educational training program for family caregivers. The program consisted of four successive weekly structured workshops held at community facilities. Each of the four workshops included an eight-hour education of caregiver training. The intensive training comprised three main components: (1) general information about dementia, (2) medical and welfare services for individuals with dementia, (3) communication skills, environment modification and strategies to manage behavioral problems. In addition, caregivers were encouraged to join support groups that were held once a month. The program instructors and group leaders were professionals with varied backgrounds, including nursing, social work, psychology, psychiatry, and neurology. The program was supported by Catholic Sanipax Socio-Medical Service & Education Foundation, a nonprofit charitable organization supporting medical affairs and education in Taiwan.

2.2. Participants

The participants in this study were recruited from family caregivers that attended the program of dementia service group in Taipei. To be included the program, family caregivers had to be 20 years or older, living with individuals diagnosed with dementia in the 6 months prior to the launch of the study, and affording primary care for them. The individuals with dementia had to be diagnosed

dementia by a physician. The study protocol fulfilled the requirement of Declaration of Helsinki: ethical principles for medical research involving human subjects and all participants gave written informed consent.

2.3. Measurement

All caregivers were interviewed by a well-trained study nurse. A repeated assessments design, included pre-intervention, post-intervention (at 3, 6 and 9 months), was used to evaluate the effectiveness of the intervention for caregivers. The measurements included: (1) socio-demographic data and clinical information of dyads (2) The Chinese version Zarit Burden Interview (ZBI)¹⁸, a caregiver self-report measure, was used to determine the level of burden perceived by caregivers. The ZBI consists of 22 items that involve a response on a 5-point Likert-type scale, ranging from 0 (never) to 4 (nearly always), with higher scores indicating increased caregiver burden. (3) The 12-item Chinese version of General Health Questionnaire (GHQ-12)¹⁹ was conducted to assess psychological morbidity in caregivers. GHQ-12 is a self-administered screening questionnaire, each item on the scale has four responses from “better than usual” to “much less than usual”, aimed at detecting individuals with a common mental disorders. The higher scores indicating increased the possibility of psychological morbidity. (4) The Medical Outcome Study 36-item Short-Form Health Survey (SF-36), a self-report questionnaire, was constructed using the Likert method of summated ratings. Four answers to each question are scored. The raw scale scores for each health concept which are then transformed to a 0–100 scale. The SF-36 can also be divided into two aggregate summary measures: the physical component summary (PCS) and the mental component summary (MCS)²⁰. The PCS and MCS can represent physical wellbeing and psychological wellbeing, respectively. In addition, all patients were evaluated by Activities of Daily Living (ADL)²¹, Instrumental Activities of Daily Living (IADL)²², and Clinical Dementia Rating Scale (CDR)²³.

2.4. Data analysis

Data were analyzed using SPSS 22.0 (IBM, Armonk, NY). Descriptive statistics was expressed as simple means, frequencies, and 95% confidence intervals. The Wilcoxon rank signed tests were used in the comparisons of patients' ADL, IADL, and CDR at different time points. Pre–post comparisons were made using general estimate equations (GEE) to confirm the longitudinal effects of the intervention for caregivers. The GEE method, introduced by Liang and Zeger²⁴, is a strategy for analysis of repeated measurements over time. It provides a way to deal with time-dependent variables. A value of $p < 0.05$ was considered statistically significant.

3. Result

A total of 53 dyads met the study criteria, of whom 34 (64.2%) dyads completed total assessments, 19 dyads (35.8%) failed to complete longitudinal follow-up, including 2 dyads were unable to contact, 13 dyads refused to be reassessed, and 4 patients deceased. To compare with the respondents, there were no significant differences in demographic characteristics. Other sociodemographic information is shown in Table 1.

The functional status of patients was evaluated by CDR, ADL and IADL. There were significant deteriorations at 9 months' follow-up. Table 2 illustrates patients' functional status at baseline, 3-month, 6-month and 9-month.

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