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Research Paper

Home-based caregiver training: Benefits differ by care receivers' dementia diagnosis

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ABSTRACT

Patients with dementia differ in their behavioral and psychological symptoms according to their diagnosis with Alzheimer's disease (AD) or vascular dementia (VaD), requiring different symptom-management strategies. This study analyzed data from a sub-sample of a randomized clinical trial to determine the effects of a home-based training program on family caregivers of patients with dementia in northern Taiwan. Our sub-sample comprised patient-caregiver dyads (46 VaD and 68 AD patients) followed for 18 months. Caregivers of AD patients in the intervention group had better competence, preparedness, health-related quality of life, and fewer depressive symptoms than those in the control group. Caregivers of VaD patients in the intervention group had better competence and health-related quality of life than those in the control group. The training program benefited family caregivers of AD patients more than caregivers of VaD patients. Specific training programs need to be developed for family caregivers of VaD patients.

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Introduction

Patients with Alzheimer's disease (AD) and patients with vascular dementia (VaD) differ in behavioral problems and psychiatric symptoms.^{1–4} For example, patients with AD have more behavioral problems, including sleep disturbance, nighttime

behaviors, appetite changes, aberrant motor behavior, and wandering behavior, than patients with VaD.^{1–4} Similarly, patients with severe AD had more disease symptoms and personality changes and were less able to cope with everyday tasks than patients with severe VaD.⁵

These differences in patients with dementia affect their family caregivers. Indeed, when patients' dementia is mild, caregivers of VaD patients had more burden than caregivers of AD patients,^{5,6} but when dementia is severe, burden is greater for caregivers of VaD patients.⁵ VaD patients in some studies had more depressive symptoms, anxiety, and psychiatric symptoms than those with AD,^{2,3,7,8} and their caregivers had poorer health-related quality of life (HRQoL) than caregivers of AD patients in the dimensions of role disability due to physical health problems, bodily pain, social function, and the physical component summary of the Medical Outcomes Study Short-Form-36 (SF-36).⁹

When family caregivers of AD patients received psychosocial training, their burden and depressive symptoms decreased, while

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their HRQoL (SF-36 scores) improved.¹⁰ Similarly, when AD patients were transitioning to institutionalized care, their caregivers' burden and depressive symptoms decreased significantly after they received a six-session intervention program consisting of individual and family counseling, support group participation, and continuous availability of ad hoc telephone counseling.¹¹ Likewise, caregivers' overall preparedness and competence improved after participating in a home-based caregiver-training program targeting management of behavioral problems in patients with dementia.^{12,13} This training program also eventually improved caregivers' HRQoL and decreased their risk for depression.¹⁴ In other studies, home visits with or without telephone consultation and support effectively decreased depressive symptoms in family caregivers of patients with dementia.^{15,16} Intervention studies for VaD have focused on patients using various approaches, including physical and psychosocial methods,^{17,18} cognitive training and cognitive rehabilitation,^{19,20} and acupuncture,²¹ but no interventions were found for caregivers of VaD patients.

However, none of these studies examined different intervention effects for family caregivers of patients with AD and VaD. Understanding the different effects of training programs for caregivers of patients with AD from VaD can provide a basis for developing more individualized training programs for family caregivers of patients with dementia.

Therefore, the purpose of this study was to explore differences in intervention effects of the home-based caregiver-training program on the competence, preparedness, depressive symptoms, and HRQoL of family caregivers of patients with AD and VaD. The data analyzed for this study came from a subset of patient-caregiver dyads in a larger clinical trial of a training program for family caregivers of patients with AD or VaD.^{12–14} We hypothesized that since patients with AD have more behavioral problems than patients with VaD^{3,4} and this training program focused on managing behavioral problems, the intervention effects on preparedness and competence for behavioral management would be better for family caregivers of patients with AD than caregivers of patients with VaD, resulting in greater improvement of caregiver HRQoL and depressive symptoms.

Methods

Design

This study was a secondary analysis of data from a sub-sample of dementia patient-family caregiver dyads in a randomized clinical trial of a training program for caregivers of patients with AD or VaD. The original study randomly assigned dementia patient-family caregiver dyads into intervention or control groups.^{13,14} Details of the original study groups are presented below in the caregiving-training program section.

Participants

Patients in the original study were 1) ≥ 65 years old and diagnosed with AD or VaD by a psychiatrist or neurologist based on criteria of the National Institute of Neurological and Communicative Disorders and Stroke criteria and Alzheimer's Disease and Related Disorders Association,²² 2) living in a community in northern Taiwan, and 3) scored ≥ 50 on the Cohen-Mansfield Agitation Inventory (CMAI).²³ Patients screened for the original study were excluded if they were diagnosed with dementia with Lewy bodies, fronto-temporal lobe dementia, or mixed dementia. Family caregivers were ≥ 20 years old and family members who had primary caregiving responsibility for or spent the most time caring for the patients.

The caregiver-training program

The intervention protocol was developed based on the Progressively Lowered Stress Threshold (PLST) model^{24,25} to teach family caregivers to understand and manage targeted behavioral problems and incorporated the concept of partnership, which focuses on a nurse-caregiver collaboration.²⁶ This training program was provided by two trained research nurses in two in-home sessions.^{13,14} These two nurses were trained by three specialists in gerontological nursing and community health nursing. The training program included nurse assessment of patients with dementia and their family, education to manage behavioral problems, as well as suggestions and consultation for problem behaviors. At the beginning of the study, nurses were supervised during home visits for two cases with immediate discussion afterward. The quality of the intervention was ensured by monthly case conferences and research meetings.

At the initial visit, the research nurses spent around 2 h assessing the patient with dementia, her/his family caregiver, environment, and needs for community resources, and specific behavioral problems. Nurses also developed a tentative behavioral management plan with the family caregiver. At the second home visit (1 week later), the research nurses also spent 2 h to provide a care plan, positive reinforcement strategies for specific behavioral problems, and information and referrals to community services. One week after the second visit, the nurses made a telephone consultation to give further advice regarding patients' targeted behavioral problems, caregiving skills, and using community services. Thereafter the nurses made monthly phone calls throughout the intervention period to consult with caregivers about their behavioral management skills. Caregivers in the control group received dementia health education material and monthly social contact follow-up phone calls from two different research nurses, thus avoiding contamination.

Procedure

The original study was approved by the Institutional Human Subjects Protection Committee (No. 97–1850B) and all study-site administrative departments. The research nurses approached eligible subjects at the outpatient clinics of two hospitals in the greater Taipei area and a local care-management center to explain the study goals and methods, participants' right to withdraw from the study at any time, and to obtain written consent. Those who agreed to participate were randomly assigned to the intervention or control group. A random number table was created in Excel to generate a random allocation sequence in advance (even numbers were assigned to the intervention group and odd numbers were assigned to the control group). Both groups were assessed before the intervention, and at 2 weeks, 3 months, 6 months, 12 months and 18 months following the intervention program.

Measures

Clinical dementia rating scale

Patients' dementia severity was rated by well-trained research nurses using the Clinical Dementia Rating (CDR).^{27,28} The CDR assesses six domains of cognitive and functional performance: memory, orientation, judgment and problem-solving, community affairs, home and hobbies, and personal care. CDR scores range from 0 to 3, with 0 indicating no cognitive impairment, 0.5 indicating very mild dementia, 1 indicating mild dementia, 2 indicating moderate dementia, and 3 indicating severe dementia.

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