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Research Paper

Trajectories of health-related quality of life among family caregivers of individuals with dementia: A home-based caregiver-training program matters

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ABSTRACT

To determine distinct courses of change in health-related quality of life (HRQoL) among family caregivers of individuals with dementia and how participating in a home-based caregiver-training program affects the probability of belonging to each course. Sixty three caregivers were in the intervention group, and 66 caregivers were in the control group of a single-blinded randomized clinical trial. Two distinct trajectories of HRQoL were identified: a well-functioning trajectory and a poor-functioning trajectory. Caregivers who received the training program were more likely than those who did not have a well-functioning trajectory of HRQoL over 18 months. This trajectory included bodily pain ($b = 1.02$, odds ratio [OR] = 2.76), general health perception ($b = 1.28$, OR = 3.60), social functioning ($b = 1.12$, OR = 3.05), vitality ($b = 1.51$, OR = 4.49), general mental health ($b = 1.08$, OR = 2.94), and mental component summary ($b = 1.27$, OR = 3.55). Home-based caregiver training can be considered as part of the protocol for managing patients with dementia and their caregivers.

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Introduction

The number of patients with dementia is increasing in Taiwan, creating a major caregiving burden for family caregivers, as in many other developed nations. The age-adjusted prevalence of all-cause

dementia in Taiwan was recently estimated to be 8.0%, significantly higher than previous estimates.¹ Among patients with dementia, 90% have at least one behavioral and psychological symptom, 30%–79% have neuropsychiatric symptoms, and 9%–58% exhibit agitation, delusions of persecution, wandering, or aggression.^{2–6}

Behavioral problems and neuropsychiatric symptoms of patients with dementia have significant, negative effects on family caregivers that seriously impact their health outcomes and quality of life.^{7,8} However, little information is available on heterogeneity in the health-related quality of life (HRQoL) in family caregivers of patients with dementia. On the other hand, HRQoL for 35% of caregivers for palliative care patients was found to worsen due to patients' care needs, but remained stable for the remaining caregivers.⁹ Thus, the trajectories of HRQoL for family caregivers of

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patients with dementia are likely to be heterogeneous, containing both good and poor trajectories.

Intervention programs to enhance family caregivers' ability to manage dementia care have been shown to improve their quality of life and mental health.^{10–13} For example, caregiving burden and quality of life improved in a randomized controlled trial of an information-and-psychological-support system linking case managers, dementia care services, health professionals, and referrals for Chinese caregivers of patients with dementia.¹⁴ The program prioritized problem areas for each family and formulated an individualized multidisciplinary education program on effective dementia care.¹⁴ Similarly, a structured multi-component intervention addressing caregiver depression, burden, self-care, social support and care recipient problem behaviors through 12 in-home and telephone sessions over 6 months improved the HRQoL of ethnically diverse (Hispanic, Caucasian, and African-American) caregivers.¹⁵

Most studies of intervention effects on HRQoL of family caregivers of patients with dementia have assessed HRQoL at discrete time points^{12–14} or averaged its changes over time.¹⁶ Family caregivers who received an individualized home-based training program were found to have better HRQoL in bodily pain, role disability due to emotional problems, vitality, and better mental summary score at least 6 months after receiving the program than those who did not.¹⁶ However, only average effects of the training program were shown on HRQoL. No studies were found on whether these family caregivers' HRQoL follows multiple distinct trajectories, and whether the effects of a given intervention vary across different trajectories. One statistical approach to approximating unknown trajectories across members of a population is group-based trajectory modeling, also known as group-based mixture modeling¹⁷ or latent-class growth modeling (LCGM).^{18,19} This approach was used in the current study to identify clusters of caregivers following similar trajectories of HRQoL over time. Thus, the purpose of this study was to 1) identify distinct courses of change in HRQoL over 18 months among family caregivers of patients with dementia, and 2) evaluate the effect of caregiving training on the probability that family caregivers would experience various HRQoL trajectories. Two hypotheses were tested as follows:

Hypothesis 1. Family caregivers' HRQoL during the 18 months after the training program will follow distinct courses or trajectories that can be characterized as well-functioning and poor-functioning.

Hypothesis 2. Caregivers who receive the individualized caregiver-training program will be more likely than those who receive no training to have HRQoL that follows a well-functioning trajectory.

Methods

Design

A single-blinded randomized clinical trial was used to evaluate the effects of a home-based training program for family caregivers of patients with dementia. After completing the training program, caregivers were followed for 18 months to assess their HRQoL and caring outcomes.

Participants

To be included in the study, family caregivers had to be (1) at least 20 years old, and (2) have primary care responsibility for the patient with dementia. Caregivers were excluded by these criteria: (1) suffering from critical illness or psychosis or a (2) paid caretaker.

Patients with dementia were included by these criteria: (1) at least 65 years old, (2) living in a home setting in northern Taiwan, (3) diagnosed with dementia by a neurologist, and (4) exhibiting behavioral problems that scored at least 50 points on the Cohen-Mansfield Agitation Inventory (CMAI).²⁰ Patients with dementia were excluded if they suffered from critical illness or psychosis.

Among the 251 family caregivers who met the inclusion criteria, 129 (51.4%) consented to participate in the study and were randomly assigned to the training program intervention ($n = 63$) or control ($n = 66$) group (Fig. 1). During the follow-up period, 44 participants dropped out because of caregivers' refusal to continue ($n = 21$), loss of contact with or relocation of caregiver ($n = 10$), patients' death ($n = 6$), institutionalization or hospitalization ($n = 5$), and change in family caregiver ($n = 2$). As the participants who dropped out still provided partial data, they were included in the analysis based on the assumption of missing at random. However, dropouts were flagged in the multivariate analysis to minimize the bias of selective attrition. At the end of the 18-month follow-up after completing the training program, 85 family caregivers remained in the study (40 in the intervention and 45 in the control group).

Since group-based trajectory modeling, group-based mixture modeling or LCGM was used in this study to identify HRQoL trajectories, a data set of at least 300 to 500 observations was preferable.¹⁸ In this data set, HRQoL dimensions were measured 6 times; for 129 participants, 649 measurements were included in the analysis. Therefore, this sample size was sufficient for the current analysis.

Caregiver-training program

The training program was an individualized, home-based consultation and education program delivered by an experienced geriatric nurse via home visits.^{16,21} This program stressed the importance for the nurse to establish a partnership with the family caregiver to collaboratively develop a care plan.²² The program also aimed to help family caregivers detect and decrease environmental stimuli for a specific dementia-related behavioral problem based on the theory of Progressively Lowered Stress Threshold (PLST).^{23–25} The PLST model assumes that the agitated behaviors of patients with dementia are caused by excessive demands from environmental and internal stimuli. Thus, appropriate control of excessive stimuli would decrease the agitated behavior.

This training program consisted of two weekly sessions, each lasting 2–3 h. Following the training sessions, further assurance and consultation were provided in monthly telephone follow-ups, and progress in behavior management was evaluated.^{16,21} During the first home visit, a geriatric nurse made a structured assessment and helped the family caregiver identify specific dementia-related problem behaviors and explored the causative environmental stimuli with the caregiver to develop tentative intervention strategies. In the second session, the nurse followed up on the outcomes of the behavior problem-management strategies and revised the management plan. In contrast, the control group received general information on dementia care and follow-up phone calls simply to maintain contact, but without any training for developing a behavioral problem-management plan and strategies.

Measures

Family caregivers' HRQoL was measured using the Taiwan-version Medical Outcomes Study 36-Item Short Form Survey (SF-36).^{26,27} Items on the SF-36 represent eight generic health concepts: physical functioning (PF), role disability due to physical health problems (RP); bodily pain (BP); vitality (energy/fatigue) (VT); general health perceptions (GH); social functioning (SF); role disability

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