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Dementia care costs and the patient's quality of life (QoL) in Taiwan: Home versus institutional care services

Yu-Chun Kuo [a,b], Chung-Fu Lan [b,c,*], Liang-Kung Chen [d,e,f], Virginia M. Lan [g]

[a] *Institute of Health and Welfare Policy, National Yang Ming University School of Medicine, No. 155, Section 2, Li-Nong Street, Taipei, 11221, Taiwan*
[b] *Institute of Health Policy and Management, National Taiwan University, No. 17, Hsu-Chow Rd., Taipei, 100, Taiwan*
[c] *Research Center of Health and Welfare Policy, National Yang Ming University School of Medicine, No. 155, Section 2, Li-Nong Street, Taipei, 11221, Taiwan*
[d] *Division of Geriatric Medicine, Department of Family Medicine, Taipei Veterans General Hospital, No. 201, Section 2, Shih-Pai Road, Taipei, 11217, Taiwan*
[e] *Center for Geriatrics and Gerontology, Taipei Veterans General Hospital, No. 201, Section 2, Shih-Pai Road, Taipei, 11217, Taiwan*
[f] *National Yang Ming University School of Medicine, No. 115, Li-Nong Street, Taipei, 11217, Taiwan*
[g] *School of Nursing, Eastern Michigan University, 341 Marshall Building, Ypsilanti, MI 48197, USA*

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ABSTRACT

Organizing optimal care for demented older people is a complex health care issue. Controversies of service models for demented patients should be balanced between cost of care, placement, and quality of life (QoL). The main purpose of this study was to explore the optimal model of dementia care in Taiwan by evaluating the care cost, patients' QoL and healthcare settings. Overall, 140 pairs of demented patients and their primary informal caregivers were enrolled (89 community-living and 51 institute-living). Compared to institute-living subjects, community-living subjects were significantly better in cognition, physical function and QoL. The annual direct cost of institutional care was significantly higher than community care (464,193 New Taiwanese Dollar (NTD) vs. 144,047 (NTD), $p < 0.001$), but indirect cost was significantly higher in home care (287,904 NTD vs. 35,665 NTD, $p < 0.001$). The care cost of home care subjects with low physical dependence was significantly lower than institutional care subjects, but the care cost of home care subjects with high physical dependence was significantly higher than institutional care subjects. Physical dependence was the significant determinant of QoL for demented patients in this study. In conclusion, demented patients with low physical dependence may be cared in the communities with support and those who had high physical dependence may be cared in the institutes in terms of the balance of QoL and the care cost.

1. Introduction

Taiwan has become an aging society (people age over 65 exceeds 7% of total population) in 1993 and is estimated to become an aged society (elderly population exceeds 14% of total population) within 25 years, which makes Taiwan the most rapidly aging country in the world. To cope with the impact of population aging, creating an age-friendly health care system is of great importance, which certainly includes providing an optimal model of dementia care. The prevalence of dementia rises along with population aging (Dong et al., 2007), and may become an unavoidable challenge to the healthcare system. The estimate of worldwide dementia care burden indicated that the global direct cost of dementia reached 156.2 billion USD, including 0.5 billion USD in Africa, 3.0 billion USD in Latin America, 52.6 billion USD in North America, 32.0 billion USD in Asia, 65. 8 billion USD in Europe, and 2.3 billion USD in Oceania (Wimo et al., 2006). Aside from the direct cost of dementia care, the informal cost of community-living demented patients is a hidden burden to the societies, which is often underestimated (Moore et al., 2001). The National Advisory Council on Aging estimated that the cost of caring a demented patient was similar between community-living and institutionalized patients (approximately 56,000 USD/patient/year). However, the majority of cost for caring community-living demented patients was unpaid informal care-giving, which was 2.5–3-folds higher than the formal care cost in the communities (Huang et al., 1988). It is generally believed that caring demented patients in the communities is costly, and the unpaid cost of informal caregiver is significantly higher than the direct cost (Ernst and Hay, 1994).

In Taiwan, a previous study showed that home-based dementia care is more expensive than institutional care when the family

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* Corresponding author at: Institute of Health Policy and Management, National Taiwan University, No. 17, Hsu-Chow Rd., Taipei, 100, Taiwan.
Tel.: +886 2 2826 7051; fax: +886 2 2827 3673.
E-mail address: cflan@ym.edu.tw (C.-F. Lan).

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labor cost is considered (Chiu et al., 1999). Another study also found that caring people with high physical dependence at home is more expensive than nursing facilities (Chiu et al., 2000). Theoretically, dementia care cost may be reduced when an optimal care model is applied to slow down physical and cognitive decline (Leon et al., 1998). However, determining the optimal dementia care model deserves extensive medico-socio-cultural considerations as well as economic analysis. Therefore, the main purpose of this study is to explore the optimal model of dementia care in Taiwan by balancing the care cost and quality of life (QoL) of demented patients in community care and institutional care settings.

2. Methods

2.1. Participants

From December 2007 to May 2008, patients visiting Neurology and Psychiatry departments of Taipei Veterans Hospital and Song-De Branch of Taipei City Hospital were invited for study. Meanwhile, residents of two dementia care institutes in Taipei City were invited for study as the institutional care group. Once the patients and their families agreed to participate in the study and signed the informed consent, a face-to-face interview would be performed by the research staff to evaluate the cost analysis for caring the demented patients. Information of care cost was mainly from the primary informal caregivers. The whole study was approved by the Ethical Committee of the National Yang Ming University.

2.2. Measurements

A semi-structured questionnaire was performed for all participating informal caregivers to explore the informal care cost and the health status of demented patients. The reliability of the questionnaire has been validated by using test–retest method to confirm the stability of the results. In addition to cost analysis, demographic data of enrolled demented patients and their primary informal caregivers' socio-demographic characteristics were also collected.

Cognitive status of participating patients was evaluated by the mini-mental status examination (MMSE), and were grouped into mild dementia (MMSE score 26–21), mild to moderate dementia (MMSE score 20–15), moderate dementia (MMSE score 14–10), and severe dementia (MMSE score below 10) (Hux et al., 1998). Physical function status was measured by 100-point Barthel's index (BI) (Sulter et al., 1999; Van der Putten et al., 1999), and all subjects were classified as total dependence (BI: 0–20), high dependence (BI: 21–60), medium dependence (BI: 61–90), low dependence (BI: 91–99), and independence (BI: 100) (Gariballa et al., 1998; Kwon et al., 2004).

2.3. Direct cost estimation

As suggested before, informal care cost (direct cost) estimations included medical care, personal and other non-healthcare costs; and indirect costs included changes in the productive use of time by patients and others (Leung et al., 2003). Medical care cost included outpatient service, inpatient service, emergency service, pharmacotherapy, and other therapies related to dementia, which were calculated from out-of-pocket cost of informal caregivers. Food and equipment cost were categorized into personal cost, including nutritional supply, diapers, assistive devices, and clothing. Personal care service cost and transportation were estimated from facility or community service used and traveling related to dementia care.

2.4. Indirect cost estimation

Indirect cost is defined as the unpaid care cost provided to the demented patients (Rice et al., 2001). The two most important elements are the time costs to patients and caregivers waiting for treatment or the time spent in hospitals, and the productivity loss in paid and unpaid economic activity (Leung et al., 2003). Time spent in caring and traveling of informal caregiver for a person with dementia at home was calculated as equivalent to the cost for caring tasks carried out by home health aides. The market value of home health aid is 2000 New Taiwanese Dollar (NTD) per day, which was used to estimate the time cost of informal caregivers for caring and traveling (Chiu et al., 2000). Productivity loss for informal caregivers was calculated by economic activity changed (resign from current jobs to care the patient or shift to the part-time job from a full-time job) and asking for leave to take care of demented persons. The wage loss of each informal caregiver was estimated according to their previous salary.

2.5. Health outcome measurements

Among all instruments for health-related QoL measurements, Quality of Well-Being, European Quality of Life-5 Dimensions (EQ5D), Health Utilities Index Mark 2, and Health Utilities Index Mark 3 were more suitable for demented persons. The reliability of EQ5D, Quality of Well-Being, and Health Utilities Index Mark 3 were all over 0.70 and their content were all validated (Silberfeld et al., 2002; Naglie et al., 2006). Among the three instruments, only EQ5D has a well-validated Chinese version. Therefore, EQ5D Chinese version was selected as the instrument to measure health-related QoL in this study.

2.6. Statistical analysis

All categorical variables of home care and institutional care group (both patients and caregivers) were compared by χ^2-test. Continuous variables were compared by Student's t-test. Moreover, multiple linear regression was used to evaluate the relationship of costs (direct cost, indirect cost and total cost) and QoL. For all tests, a $p < 0.05$ was considered statistically significant.

3. Results

3.1. Demographic data

In total, 140 pairs of demented person and primary informal caregivers were enrolled (89 pairs in home care group and 51 in institutional care group). Comparisons of demographic data between home care and institutional care groups were similar, except that cognitive status, physical function and QoL were all significantly better in home care group (Table 1).

3.2. Comparisons of informal caregivers

Comparisons of age, education, and family income of primary informal caregivers were similar between home care and institutional care group. However, primary informal caregivers of home care group were more likely to be females and were spouses or children of the patients. Moreover, most informal caregivers of home care group were unemployed (Table 2).

3.3. Cost estimation

Compared with home care, the direct cost was significantly higher in institutional care group (464,193 NTD vs. 144,047 NTD,