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Conflict of Interest

The authors have no financial conflicts of
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Survey of Current Status and Cognition of Activities of Daily Living in Dementia Patients: the 2018 “Il-sang-ye-chan” Campaign

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ABSTRACT

Background and Purpose: Disability associated with activities of daily living (ADL) is the basis of dementia diagnosis and is an important factor in the care of dementia patients. The status of awareness and burden of ADL disability in dementia patients was investigated six years ago and used as an important reference for “Il-sang-ye-chan” campaign. They were re-investigated in six years and compared with previous results.

Methods: The survey included caregivers of 100 dementia patients listed at the four regional dementia centers. Structured open and closed questions about ADL were asked. Assessments included age, sex, education level, economic status, severity of dementia, caregiving pattern, current statuses and cognition of ADL, and caregiver needs.

Results: The cognition of ADL was still very low (43%). Increased stress among caregivers was the biggest burden, and they frequently suffered from outing disability (56%), recent memory loss (48%), and loss of bowel/bladder control (40%). The economic burden has been greatly reduced compared with the burden six years ago and the needs of caregivers were still highly about educational guide lines or programs.

Conclusions: Continued interest and further investigation into ADL disability of dementia patients are needed. Korean Dementia Association will further expand the “Il-sang-ye-chan” program: via a multi-domain cognitive intervention program under the Care for ADL in dementia and Relieve symptoms in Dementia Project.

Keywords: Activities of daily living; Dementia; Caregivers

INTRODUCTION

Activities of daily living (ADL) are defined by the ability to carry out basic activities required for self-care and complex activities to maintain social and occupational relationships.¹⁻³ ADL disability is the prerequisite for the diagnosis of dementia and treatment of patients

Author Contributions

Conceptualization: Choi H, Park KH, Kim SH, Lee CN. Formal analysis: Choi H, Kim SH, Lee CN. Investigation: Choi H, Lim JS, Moon Y, Lee CN. Methodology: Choi H, Lim JS, Moon Y, Lee CN. Project administration: Choi H, Lim JS, Moon Y, Lee CN. Supervision: Park KH. Writing - original draft: Choi H. Writing - review & editing: Choi H, Park KH, Kim SH, Lee CN.

with dementia.⁴ In addition, it is one of the major decisive factors associated with mortality in advanced stages of dementia and contributes to caregiver burden. Furthermore, it is the most important index for the estimation of social expenses in the management of patients with dementia.⁵⁻⁹

The Korean Dementia Association (KDA) conducted the “Il-sang-ye-chan” campaign since 2012 to raise the awareness of disability associated with ADL in patients with dementia and facilitated empirical programs to alleviate the suffering and disability of such patients and their caregivers. Since the inception of “Il-sang-ye-chan” program six years ago, the “Awareness of ADL in Patients with Dementia” was implemented to recognize the efforts of caregivers and their burden. The results were used to implement the “Il-sang-ye-chan” program and provide the basic data for the development of a national policy proposal for dementia management. For the past 6 years, a number of changes involved the social system and awareness of dementia management in South Korea. Accordingly, an apparently large gap existed in the recognition of ADL ability among patients with dementia and the caregiver burden. Therefore, this study re-investigated the ‘Awareness of ADL in Patients with Dementia’ and compared the results with data obtained six years ago to design a policy for patients with dementia and maintain their ability for AD. We also discussed the direction of the relevant study at the level of “Il-sang-ye-chan” campaign as well as academic associations.

METHODS

Subject

Compared with previous studies, this investigation involved caregivers of patients who were diagnosed with dementia at medical institutions and Dementia Healthcare Center programs at the local levels including Gangbuk-gu (Seoul), Gwangjin-gu (Seoul), Namyangju-si (Gyeonggi) and Anyang-si (Gyeonggi) from June 1 to June 30, 2018. Only primary caregivers who worked for an average of 5 hours or longer daily and 5 days or longer each week, were included.¹⁰

Contents of survey

Similar to previous study, the survey consisted of personal data including age, gender and academic background of respondents and the patients cared by them, the type and duration of caregiving, recognition of ADL disability in patients with dementia, symptoms that increase the respondents' difficulty of patient management, caregiving burden and resulting claims by the respondent.¹⁰ In addition, the income level of caregivers was compared in order to evaluate the differences in burden based on income level. The ADL disability was classified into Physical ADL (PADL) and Instrumental ADL (IADL), collectively including 12 items such as personal hygiene, going out, dressing, managing finances, recent memory issues, bowel/bladder control, cooking, feeding, using the phone, managing medication, attending to hobbies and watching TV. PADL included four items from the Disability Assessment for Dementia-Korean version (DAD-K) such as personal hygiene, dressing, bowel/bladder control and feeding. IADL included eight items from Korean-IADL, Seoul-IADL, DAD-K such as going out, managing finances, cooking, using the phone, managing medication, recent memory, attending to a hobby and watching TV.^{11,13} Questions related to caregiving burden consisted of six items associated with patient's disability such as caregiving time, stress, health status, family turmoil, financial burden and social relationships (**Supplementary Data 1**).

Analysis

This study did not compare the characteristics of respondents and patients in the two groups with dementia with and without ADL disability, as previous studies failed to report significant results from such a comparison. Descriptive statistics of the study population are presented, and χ^2 tests were performed to examine the differences between lower and higher income groups. A $p < 0.05$ was considered statistically significant. Caregiving burden, financial burden and claims by caregivers, each of which was attributed to ADL disability in patients with dementia, were analyzed in comparison with the results from the previous study.

RESULTS

Recognition of ADL and general characteristics of respondents

A total of 43 out of 100 respondents confirmed their awareness of patient's ADL ability, compared with less than 51 of 100 respondents investigated in a previous survey conducted six years ago.¹⁰ The mean ages of caregivers and patients were 54.9 and 80.1 years, respectively. The proportion of females was 75/100 and 52/100, respectively. In terms of income level, 46 respondents reported a monthly income under KRW 2,000,000 compared with 10 respondents with greater than KRW 4,000,000. The mean duration of symptoms in patients diagnosed with dementia was 39.4 months and the severity of symptoms was mild in 43 patients and severe in 19 patients (Table 1).

Caregiving burden due to ADL disability in patients with dementia

Increased stress experienced by caregivers attending to dementia patients with ADL disability accounted for the largest burden for the caregivers in this study (Fig. 1A; 71%) compared with increased duration of caregiving reported in previous study (Fig. 1B; 84%). The burden included deterioration of social relationships and health status, followed by increased economic and family burden (Fig. 1A). Economic burden (78%→56%) and deterioration of health status (70%→52%) were substantially decreased compared with the previous study. More specifically, the most frequent disability experienced by the caregivers was ‘going out,’ followed by ‘managing finances,’ ‘recent memory,’ ‘managing medication,’ and ‘personal hygiene’ (Fig. 2A) and the largest burden involved ‘going out’ followed by issues related

Table 1. Characteristics of respondents and patients

Respondents	Number (total number=100)
Understanding ADL	43
Age (yr)	
Caregiver	54.9±12.2
Patients	80.1±7.2
Female	
Caregiver	75
Patients	52
Monthly income (1,000 won)	
Under 2,000	46
2,000–4,000	44
Over 4,000	10
Duration of symptoms (mon)	39.4±12.1
Severity of patients	
Mild	43
Moderate	38
Severe	19

Data are expressed as number, mean±standard deviation.
ADL: activities of daily living.

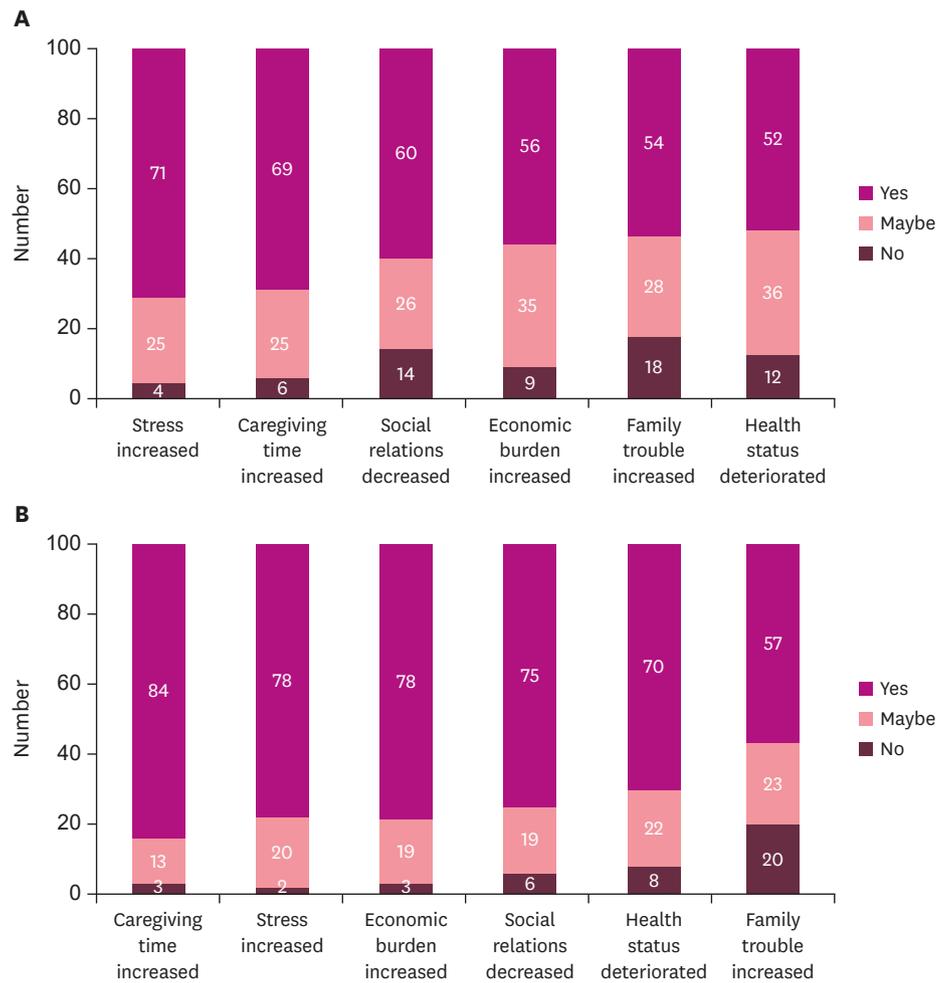


Fig. 1. Prevalence of patterns of caregiver burden. (A) Prevalence of patterns of caregiver burden in 2018. (B) Prevalence of patterns of caregiver burden in 2012.

to ‘recent memory,’ ‘bowel/bladder control’ and ‘personal hygiene’ (Fig. 2B) similar to the previous study (Fig. 2C and D).

Economic burden caused by ADL disability in patients with dementia

In this study, 33% of respondents reduced their working hours by a mean duration of 10.3 hours and 14% of respondents quit their job, suggesting significant improvement compared with the study conducted six years ago (Fig. 3A). In the previous study, 51% of respondents were found to reduce their working hours to devote time for patient caregiving, with a mean reduction of 14.55 hours per week. The results showed that 27% of respondents quit their job, and 78% of the total respondents were found to be hindered in their career or quit their job (Fig. 3B). However, there was still a big difference in the type of caregiving based on income levels: 20% of respondents whose monthly income was under KRW 2,000,000 were assisted by professional caregiving personnel towards costs while 60% still encountered difficulties associated with full caregiving. Meanwhile, 60% of respondents whose monthly income exceeded KRW 4,000,000 derived cost-bearing support from professional caregivers while 20% provided full caregiving support. Such a difference between the two groups at different income levels was statistically significant (Table 2, $p < 0.01$).

The Survey for ADL: “il-sang-ye-chan” Campaign

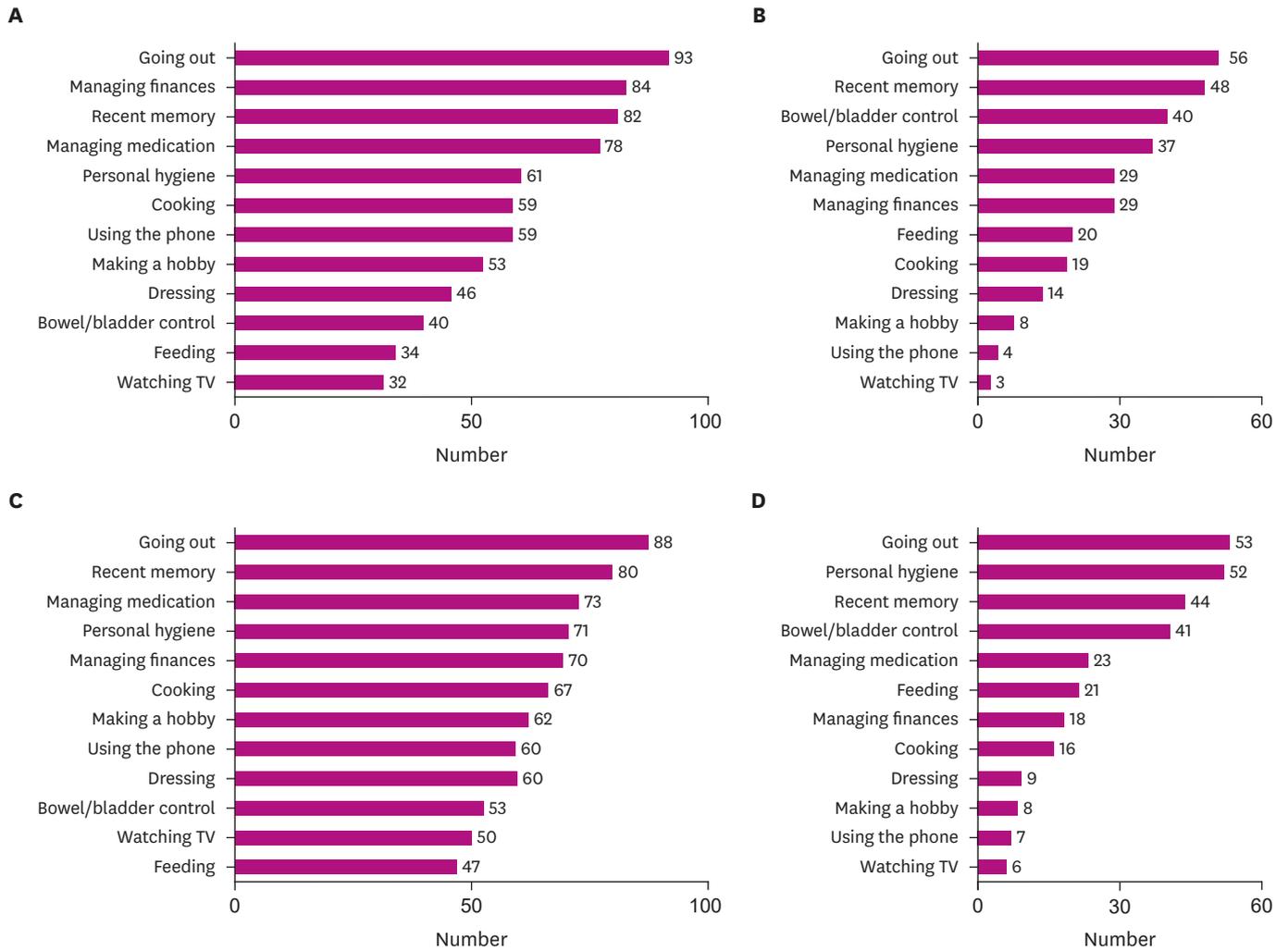


Fig. 2. Prevalence of activities of daily living disability in dementia patients. (A) Prevalence of symptoms that caregiver experienced in 2018. (B) Prevalence of symptoms that seriously bothered caregiver in 2018. (C) Prevalence of symptoms that caregiver experienced in 2012. (D) Prevalence of symptoms that seriously bothered caregiver in 2012.

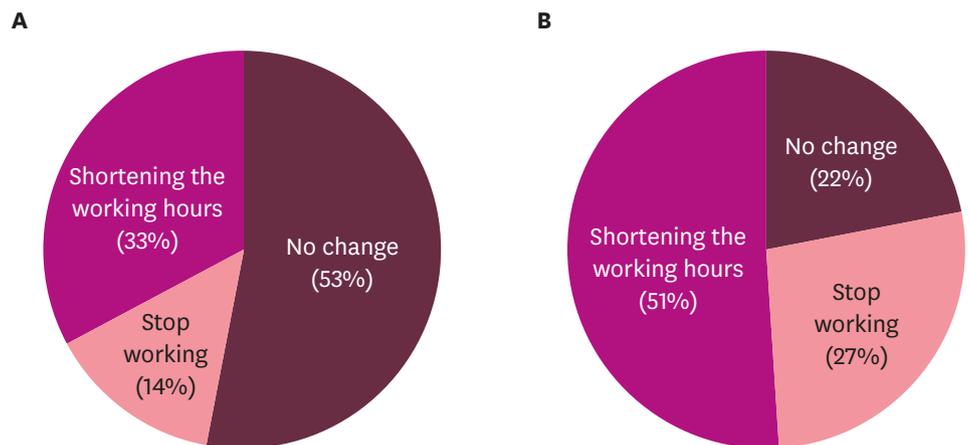


Fig. 3. The economic burden of caregivers for dementia patients. (A) The economic burden of caregivers for dementia patients in 2018. The average of shortening the working hours: 10.3 hours/week. (B) The economic burden of caregivers for dementia patients in 2012. The average of shortening the working hours: 14.55 hours/week.

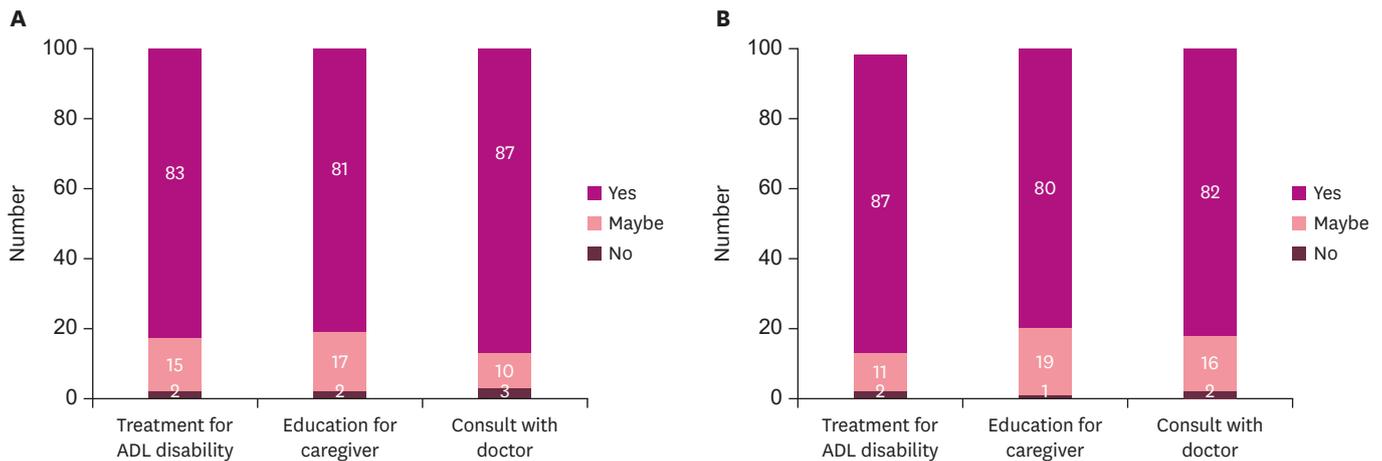


Fig. 4. Needs of caregivers for dementia patients. (A) Needs of caregivers for dementia patients in 2018. (B) Needs of caregivers for dementia patients in 2012. ADL: activities of daily living.

Table 2. Effect of familial economic status on caregiving patterns

Caregiving patterns	Lower-income group*	Higher-income group†	p
One family member was wholly charged	66	20	<0.01
Rotated their family members	14	20	
Rotated professional caregiver	12	10	
Professional caregivers were wholly charged	8	50	

Data are expressed as percentage.

*Monthly familial income was below 2,000,000 won; †Monthly familial income was over 4,000,000 won.

Claim by caregivers in relation to ADL disability in patients with dementia

Caregiver claims in relation to ADL disability in patients with dementia were still significantly high. The proportion of respondents who claimed consultation with a dementia specialist was the highest (87%), followed by claims for training in dementia management (81%) and claims for treatment to improve patients ADL ability (83%). The results were not substantially different from previous study (Fig. 4).

DISCUSSION

The results of survey showed that recognition of ADL disability was only limited to 43% of respondents even though it was one of the important factors in the diagnosis of dementia and patient management (Table 1). It still falls short of 51% recognition reported in the previous study under the “Il-sang-ye-chan” campaign that started six years ago. Considering the importance of caregiver training for appropriate treatment and management of patients with dementia, public relations activities for “Il-sang-ye-chan” campaign should be actively undertaken to reflect the national dementia policy. Similar to the results of previous study, this study showed that caregivers of patients with dementia have a major difficulty involving ‘active exploration by patients and displayed burdens associated with recent memory disorder, bowel/bladder control and personal hygiene (Fig. 2C and D). Similar to the investigations conducted six years ago, this study confirmed the urgent need for programs or systems to facilitate routine activities by patients and their caregivers, which requires further consideration of the difficulties faced by caregivers planning for the Dementia Healthcare Center activities of patients and their caregivers.

Meanwhile, the caregiver burden was significantly reduced from the levels reported in the six-year-old study. Nearly 78% of caregivers quitting their job or reducing their working hours due to ADL disability among patients in the previous study, which significantly adversely affected the low-income class, and was promptly addressed as reported several times in press releases and policy discussions.¹⁰ In this study, the proportion of respondents who reduced their working hours was decreased to 33% with reduced number of working hours from a mean of 14.55 to 10.3 hours. The proportion of respondents who quit their job decreased from 27% to 14%, indicating that the economic burden for caregivers due to patients with dementia has been largely improved, compared to the six-year-old study (**Fig. 3B**). Furthermore, the economic burden and deteriorating health status of the caregivers was largely decreased, confirming the improvement in economic and physical improvement of the caregivers (**Fig. 1**). As a result of steady implementation of dementia management policy by the government for the last six years, the long-term care insurance for the elderly and creation of dementia healthcare centers increased the social interest in dementia issues. However, the gap in securing cost-bearing support from professional caregivers at different income levels persisted. For low income level, the rate of self-caregiving was still high, increased stress, decreased social activities and deteriorated health status.^{14,15}

Lastly, for claims initiated by caregivers in relation to disability of ADL in patients, more than 80% of respondents were willing to participate in treatment or training programs, indicating active interest. Accordingly, the medical staff specializing in dementia need to reflect on their practice and reimbursement system to reorganize the activity of medical staff. In addition, the efforts of academic associations increasingly interested in developing the relevant programs should be encouraged. The “Il-sang-ye-chan” program currently ongoing may further support patients with dementia and their caregivers.

This study had a limited number of subjects including less than 100 caregivers at the Dementia Healthcare Center in the metropolitan area and involved unclear classification of patients with dementia by disease. Nonetheless, this study elucidates the current status vis-a-vis the ADL ability of patients with dementia and their caregivers as well as provides suggestions to improve the ADL ability of patients with dementia, compared with the six-year-old study. The findings are expected to facilitate the establishment of policies for caregivers of patients with dementia and continuation of ‘Il-sang-ye-chan campaign’ in the future.

Recently, much attention has been focused on multi-domain cognitive intervention; however, in the case of patients who are already diagnosed with dementia, it is difficult to expect recovery of cognitive function through such non-pharmacological treatments.^{16,17} KDA has been conducting an educational program with the National Museum of Contemporary Art for the past four years, and also published guidelines about ADL in dementia, which were distributed to dementia patients and caregivers. Such activities found in the survey study indicated that the high degree of satisfaction in patients with dementia and their caregivers, improved ADL of dementia patients, reduced depression in patients and the caregiver burden.¹⁸ Based on these results, KDA will expand the “Il-sang-ye-chan” program by developing a multi-domain cognitive intervention program in collaboration with various institutions interested in managing dementia in patients. KDA has proposed a long-term Care for ADL in dementia and Relieve symptoms in Dementia Project. In addition, we will continue to pursue our interests and efforts to provide practical assistance to patients and their families suffering from impaired ADL in dementia.

SUPPLEMENTARY MATERIAL

Supplementary Data 1

Questionnaire (Korean ver.)

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