

## ORIGINAL RESEARCH

# Development of a home-based, comprehensive intervention program for family caregivers of dementia patients

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## ABSTRACT

**Objective:** This study aims to develop a home-based and comprehensive education program for family caregivers who take care of the elderly with dementia at home.

**Methods:** The contents and approach methods of the preliminary program were developed by reviewing previous programs. The final program and intervention materials were determined by confirmation of the content validity by experts and clinical validity by caregivers of the elderly with dementia.

**Results:** The intervention contents selected for caregivers consisted of 6 concepts, 15 themes, and 37 items. The six main concepts were as follows: emotional support, knowledge improvement, skills training, self-care ability, communication, and use of resource. The program was scheduled for six weeks, and home visits, supportive phone-calls, and group meetings were offered to caregivers. Intervention materials included workbook, manuals, and charts.

**Conclusions:** An intensive and comprehensive intervention including diversified contents based on individual approaches should be utilized to decrease the negative experiences of caregivers who take care of the elderly with dementia.

**Key Words:** Family caregivers, Dementia, Program development, Written material

## 1. INTRODUCTION

The percentage of the elderly population is increasing every year because of an extended life expectancy and reduced fertility rate. Korea was defined as an aging society in 2000, when people aged 65 and older exceeded 7% of the total population. Their total number is 5,193,000 and comprised approximately 10.7% of the total Korean population in a 2009 elderly survey; they are estimated to comprise approximately 14% of the total population in 2018.<sup>[1,2]</sup>

It is difficult to know the exact number of people with senile dementia in Korea; however, in a nationwide study on the prevalence of dementia, dementia patients over the age of 65 were approximately 8.4% (total 421,387; men 163,451, women 257,936) of the population.<sup>[3]</sup> That same study reported that the number of dementia patients will increase 2 times every 20 years due to rapid ageing. This issue is expected to emerge as a significant problem for Korean society in the future.<sup>[4]</sup>

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Many dementia patients need help from other people. In most cases, patients' family members take care of them in Korea because of cultural characteristics, such as family obligation<sup>[4]</sup> so dementia is one of the stressors affecting the whole family. People with dementia live, on average, 7 to 10 years after diagnosis, and most of those years are spent at home.<sup>[5]</sup> Accordingly, family members spend a lot of time with them, taking care of them. Caring for a person with dementia is a difficult and often overwhelming task and more and more people are facing this challenge.<sup>[5]</sup> Therefore, both the people with dementia and their family members should be considered as part of the nursing client.

Chenweth and Spencer said that family cohesion and the self-esteem of the primary caregiver increased when family members were well adapted to the stressors caused by dementia patients.<sup>[6]</sup> However, most researchers mentioned that the family experienced more negative changes than positive changes,<sup>[7]</sup> and the negative outcomes experienced by family members living with people with dementia can appear both psychologically and physically. Generally, negative experiences were as follows: depressive disorder,<sup>[8-10]</sup> anxiety disorder,<sup>[9-11]</sup> lower levels of life satisfaction,<sup>[12]</sup> burden,<sup>[9, 10, 13, 14]</sup> loss of self,<sup>[15]</sup> prolonged distress,<sup>[15]</sup> emotional strain,<sup>[16]</sup> family conflict,<sup>[17, 18]</sup> decreased quality of life,<sup>[19]</sup> decrease in preventive health behaviors,<sup>[18]</sup> decrements in immunity measures,<sup>[11, 20]</sup> fatigue,<sup>[21]</sup> and a worsening of headaches, insomnia, and digestive symptoms.<sup>[22]</sup> That is to say, many family caregivers, especially caregivers at home without the help of experts, experience suffering and difficulty while taking care of the elderly with dementia. Accordingly, family caregivers need professional help.

In recent years, researchers have done an increasing number of clinical trials for family caregivers of the elderly with dementia in order to reduce their difficulties and to help them.<sup>[23]</sup> Previous studies on interventions for caregivers generally used programs, which consisted of a single-component or a few components such as emotional and educational support, and stress management. However, Schultz and Martire described that interventions combining various contents and different strategies were more effective than single-component interventions in a study on "Stress/Health model" applied to caregiving & associated intervention.<sup>[15]</sup> In addition, the intervention approach in previous studies was usually in the form of group meetings or sessions.<sup>[24-26]</sup> However, most caregivers taking care of the elderly with dementia without professional help at home cannot participate in group meetings or sessions unless other people look after the patient. In other words, a community or home-based approach is needed.<sup>[27]</sup>

Therefore, the aim of this study was to develop a home-based and comprehensive intervention program for family caregivers who take care of the elderly with dementia at home.

## 2. METHODS

### 2.1 Research design

This study was on developing a program for family caregivers who take care of the elderly with dementia at home.

### 2.2 Research procedures

The program development stages are as follows and presented in Figure 1. The program was developed on the basis of the phase of ADDIE (Analysis, Design, Development, Implementation, Evaluation) by Seels & Richey.<sup>[28]</sup>

#### 2.2.1 Determine the needs of the family caregiver and contents and strategies of previous programs through a literature review

The needs of family caregivers were determined by a literature review in order to develop specific contents for the intervention. Cho noticed the highest need of family caregivers consisted of 4 sub-dimensions (knowledge of dementia and dementia patients' management, skills for caring for dementia patients, services for family caregivers, and community resources connection);<sup>[29]</sup> therefore, 17 items with the highest demand within the 4 sub-dimensions were included in this study. To determine more appropriate intervention contents and strategies, previous research was reviewed. CINAHL, MEDLINE, KISS, and RISS, free search engines for accessing databases, were used to search for articles on related topics. A total of 51 international articles and 20 Korean articles (including master's theses and Ph.D. dissertations since there were only a few related articles) were retrieved from the four search engines using the following terms: dementia and caregiver; dementia and family; Alzheimer and caregiver; and Alzheimer and family. At the same time, three conditions, namely, clinical trial (type of article), and English (language), were attached as limit conditions when the articles were retrieved on CINAHL and MEDLINE. In addition, two conditions, namely, clinical trial (type of article) and Korean (language) were added on KISS and RISS. However, caregivers who took care of Huntington disease patients were excluded because dementia patients caused by that disease are rare in Korea. Finally, 18 articles fit the above search criteria and, accordingly, were analyzed.

#### 2.2.2 Development of the preliminary protocol

A preliminary protocol for the intervention included a workbook, manuals, and charts. The workbook—containing educational contents based on the six sub-concepts of intervention selected through a literature review—was developed on the basis of the needs of the family caregivers (see Table 1).

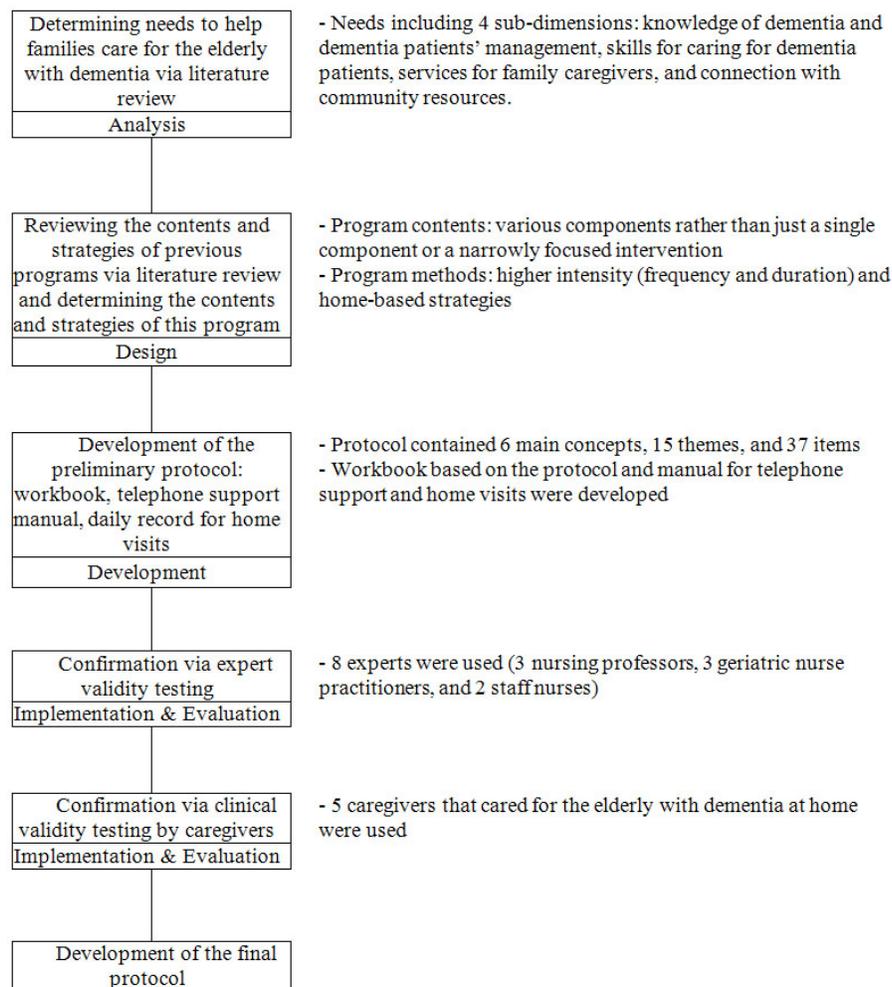
Manuals and charts were also developed preliminarily for nursing activities.

**2.2.3 Confirmation of content validity by experts**

For content validity, expert review and round-table discussion were used. The expert group consisted of three professors (two professors of geriatric nursing and one professor of community health nursing), three geriatric nurse practitioners (having extensive experience with the care of elderly patients in communities and institutions), and two dementia nurses (having three or more years of experience in local dementia centers). These eight experts were engaged in re-

viewing the two components of the intervention for content validity as outlined by Lynn:<sup>[30]</sup> the relevance of program contents and adequacy of the materials. Each item had a 4-point rating scale and asked experts to respond to each question by checking “strongly agree”, “agree”, “disagree”, or “strongly disagree” and computed a content validity index (CVI) according to the recommendations of Lynn.<sup>[30]</sup>

After expert review, this researcher and three professors conducted a round-table discussion and determined intervention contents and protocols on the basis of CVI scores and expert opinions through expert review.



**Figure 1.** Program development stages

**2.2.4 Confirmation of clinical validity by caregivers of the elderly with dementia**

After the test for content validity, clinical validity was tested by users in order to examine whether developed workbook was useful for family caregivers of dementia patients. For clinical validity, this researcher interviewed five caregivers. Caregivers were asked to review three components of the

intervention: the necessity of the contents, the adequacy of the representation, and the ease of understanding.

**2.2.5 Development of the final protocol**

After reviewing the feedback from both the experts and caregivers, the intervention protocol was revised. The workbook, manuals, and charts were then modified using the revised protocol.

**Table 1.** The results of the validity test and contents of the program

Main concept	Themes	Item	Results of the expert validity test		Results of the clinical validity test		
			Relevance of program contents	Adequacy of materials	Necessity of contents	Adequacy of representation	Ease of understanding
Emotional support	Emotional support	Psychological support between caregivers	1.00	1.00	1.00	1.00	1.00
		Encouragement of free self-expression	1.00	1.00	1.00	1.00	1.00
		Support by experts	1.00	1.00	1.00	1.00	1.00
		Maintaining changed behaviors after application of the program	1.00	1.00	1.00	1.00	1.00
Knowledge improvement	Basic information	Definition of dementia	1.00	1.00	1.00	1.00	1.00
		Cause of dementia	1.00	1.00	0.80	1.00	1.00
		Symptoms and progress of dementia	1.00	1.00	1.00	1.00	1.00
	Treatment and management	Medication	1.00	0.75	0.80	1.00	1.00
	General management and caring	1.00	1.00	0.80	1.00	1.00	
Skill training	Impaired memory management	Strategies and skills to manage impaired memory	1.00	1.00	1.00	1.00	1.00
	Psychiatric symptoms management	Strategies and skills to manage psychiatric symptoms	1.00	1.00	1.00	1.00	1.00
	Behavioral problems management	Strategies and skills to manage behavioral problems	1.00	1.00	1.00	1.00	1.00
	Care of ADL	Eating, Dressing, Toileting, Bathing	1.00	1.00	1.00	1.00	1.00
	Environmental management	Environment management for the safety of the elderly with dementia	1.00	0.75	1.00	1.00	1.00
Communication	Adaptation of family	Adaptation stage of the family	0.88	1.00	1.00	1.00	1.00
	Positive relationships with the elderly with dementia	Attitude towards the elderly with dementia	1.00	0.86	1.00	1.00	1.00
		Communication with the elderly with dementia	1.00	1.00	1.00	1.00	1.00
	Communication between family members	Communication between family members	1.00	1.00	1.00	1.00	1.00
		Sharing roles between family members	1.00	1.00	1.00	1.00	1.00
Self-care ability	Stress management	Experience feelings of family caregivers	1.00	1.00	1.00	1.00	1.00
		Life management of family caregivers	1.00	1.00	1.00	1.00	1.00
		Stress management of family caregivers	1.00	1.00	1.00	1.00	1.00
		Strategy for stress management 1: Relaxation	1.00	1.00	1.00	1.00	1.00
	Strategy for stress management 2: Massage	1.00	1.00	1.00	1.00	1.00	
	Maintaining physical health	Nutrition for family caregivers	0.75	1.00	1.00	1.00	1.00
		Physical activities for family caregivers	0.75	1.00	1.00	1.00	1.00
Preventive health behaviors for family caregivers		1.00	0.88	1.00	1.00	1.00	
Use of resource	Available services	Elderly long-term care insurance system	1.00	1.00	1.00	1.00	1.00
		Daycare center	1.00	1.00	0.40	0.60	0.60
		Short-term elderly care facilities	1.00	1.00	1.00	1.00	1.00
		Long-Term care facilities	1.00	1.00	1.00	1.00	1.00
		Visit bath services	0.75	1.00	1.00	1.00	1.00
		Dementia support center	1.00	1.00	1.00	1.00	1.00
		Service for report of disappearance	1.00	1.00	1.00	1.00	1.00
		Contact address of available services within locality	1.00	1.00	1.00	1.00	1.00
	Available program to gain information	Internet address to get help	1.00	1.00	1.00	1.00	1.00
		Book to get help	1.00	1.00	1.00	1.00	1.00

### 2.3 Ethical considerations

The study was approved by the Institutional Review Board of the Y University College of Nursing in Korea. Informed consent was obtained from all participants after explaining the aims, process, and methods of this study.

## 3. RESULTS

### 3.1 Selection of the contents and strategies of the program

Main intervention contents selected for caregivers consisted of six concepts, 15 themes, and 37 items. The six main concepts were as follows: emotional support, knowledge improvement, skills training, self-care ability, communication, and use of resources. It was also decided to use higher intensity (frequency) and home-based strategies utilizing group meetings, telephone calls, and home visits.

### 3.2 Development of the preliminary protocol: workbook, manuals, and charts

To provide standardized services for caregivers, a workbook, manuals, and semi-structured nursing record for home visits and telephone calls were developed preliminarily based on the six concepts. The workbook included essential information and performance tasks for caregivers and the manuals guided interventions and education by nurses.

### 3.3 Confirmation of the preliminary protocol: expert validity and clinical validity

The result of CVI by experts and caregivers is presented in Table 1. The minimum agreement standard by the eight experts was more than 0.75.<sup>[30]</sup>

The CVI scores for both the “relevance of program contents” and “adequacy of materials” were more than 0.75 for the test given to the experts. However, experts had some advice for parts of the materials. The comments were summarized as follows: uniformity of the terminology and some additional information on items. After reviewing the materials and a panel discussion on it, the material was revised, and the clinical validity test was carried out. In the clinical validity test determined by the caregivers, the scores for necessity, adequacy of representation, and ease of understanding in a daycare center were below 0.75.

In this study, caregivers were caring for the elderly with dementia at home. However, the information from the daycare center was maintained in the final protocol based on the experts’ advice.

### 3.4 Development of the final protocol

After review by the experts and caregivers, the intervention protocol was revised. The revised protocol contained 6 main

concepts, 15 themes, and 37 items. Workbook, manuals, and charts (including semi-structured nursing record) were modified based on the revised protocol.

The workbook had Q & As or a checklist inserted for every main concept, in order to enhance the participation of the caregivers. Charts were prepared for every caregiver and patient to maintain the continuity of care.

The program was scheduled for six weeks. Group meetings were held in the first and last week and home visits were conducted once a week from the second to fifth weeks. And telephone support was implemented every week.

### 3.5 Preliminary application of the program

The developed program was offered to five caregivers to ascertain its applicability. Nurses provided the education contents of the main theme at every home visit and group meetings for six weeks, but also applied them with flexibility depending on the knowledge level of the caregivers as well as the condition of the elderly with dementia. Nurses also provided emotional support, reinforced previous education and behavioral changes, and were assigned tasks to do until the next home visit or phone call.

The actual intervention was done by nurses each time, which included the following: 90 minutes to two hours of home visits; telephone call five to ten minutes, and caregivers group meetings for 90 minutes, respectively. Home visits and telephone calls were applied individually. In addition, assistants accompanied the nurses to the home visits to provide care for the elderly with dementia during the participation of caregivers in the program as required on occasion. However, some caregivers did not participate in the group meetings of caregivers because there was no family member to take care of the elderly on behalf of them or they refused to do so for personal reasons (*i.e.*, too busy and did not want others to know).

The satisfaction assessment was conducted after completing the program. The results are summarized in Table 2. The program satisfaction scale consists of six items, ranged from one (not at all) to 4 (very satisfactory), the average scores of six items were all above than 3 points. The highest score items were the satisfaction nurse and materials (workbook and goods provided during the program).

## 4. DISCUSSION

A caring for a family member with dementia is one of the stressors that affect the whole family. Most people live with chronic conditions such as dementia and most elderly people are supported by family members,<sup>[31]</sup> and family members spend a lot of time with the elderly to take care of them.

Thus, family members are required to learn new information and practices for care. For that reason, Schults and Martire suggested that interventions combining different strategies and providing caregivers with diverse services and support

tend to generate larger effects than narrowly-focused interventions.<sup>[15]</sup> Therefore, in this study, various contents and approach methods were adopted simultaneously depending on the needs of the caregivers.

**Table 2.** Evaluation of participants’ program satisfaction

Variables	M	SD	Range
Could get information about how to care for the elderly with dementia	3.8	0.45	3-4
Could learn skills about how to care for the elderly with dementia	3.6	0.55	3-4
Could have confidence in caring for the elderly with dementia	3.2	0.87	2-4
Be satisfied with the nurse who has provide the program	4.0	0	4
Could contact a nurse as needed	3.6	0.55	3-4
Be satisfied with the materials provided during the program	4.0	0	4

The intervention contents were applied with flexibility depending on the conditions of the caregivers and the available intervention items were varied for each caregiver. These facts are in agreement with the opinions of previous researchers such as Cho who described that health care providers should have provided practical help to caregivers, based on those diversified needs.<sup>[29]</sup> Kennet, Burgio, and Schulz also suggested a comprehensive, intensive, and individually tailored intervention to increase effectiveness.<sup>[23]</sup> Actually, recent studies also tend to provide interventions, which have included diversified service contents or supports.<sup>[27,32,33]</sup>

The program developed in this study included skill training as well as knowledge improvement. Kennet, Burgio, & Schulz mentioned that if the informative needs have been met, the caregivers might additionally desire more training on general problem solving skills as well as more specific skills in areas such as managing the patients’ behaviors.<sup>[23]</sup> Thus, it is likely that caregivers desire to learn more specific information that applies to their needs and specific situation rather than general information. Yoo and Ha reported that information about how to care was the biggest need.<sup>[34]</sup> In addition, Cho reported that the second largest need of caregivers was the skill to care for patients with dementia.<sup>[29]</sup> Thus, skill training was considered as an important part of this program. Namely, skill training by a nurse was provided depending on the situation of the caregivers at home after nurses checked for symptoms and ADLs of the elderly with dementia as well as for the environmental safety conditions of the resident.

Communication in this study included how to build a positive relationship as well as verbal communication with the elderly with dementia and other family members. Many caregivers in Korea experience distress due to unfair and heavy responsibilities; therefore, this sometimes causes a conflict

in the family, and they wish to improve difficult situations including large and small family conflicts.<sup>[4,35]</sup> Accordingly, this program included communication skills among family members and how to share roles in addition to the aforementioned intervention contents. These intervention contents are expected to be effective as family coping strategies and for providing comfortable situations.

Schulz and Martire explained that caregivers experienced not only psychological problems, but also physical health problems.<sup>[15]</sup> It is believed that psychological conditions, such as strain or stress in caregivers, affect their physical health. In addition, caregivers also tend to lessen their own health or experience physical fatigue because they spend most of their time at home caring for the elderly with dementia.<sup>[36]</sup> Thus, not only psychological symptoms, such as stress, but also physical health were included in the program. Namely, this program focused on caregivers’ individual health as well as caregivers’ abilities to care for the elderly with dementia. However, caregivers do not tend to respond to or identify with the need to care for themselves until they experience declining health of their own.<sup>[37]</sup> Accordingly, health care providers had to develop specific strategies and methods to change caregivers’ bad habits or to learn how to improve caregivers’ psychological and physical health before they experience bad health. In addition, health care providers need to emphasize that caregivers’ health can affect the conditions of the elderly and the wellness of the whole family.

Practical information about the use of resources, such as the contact address of available local services or how to obtain insurance service, was one of the most sought after help for caregivers.<sup>[38]</sup> Cho also reported that “community resources networking” was the highest need of caregivers.<sup>[29]</sup> Therefore, health care providers need to establish an integrated information center that can guide the programs and contents

for families of patients with dementia and have to actively advertise the center.

As a result of applying the program to five family caregivers who take care of dementia patients for six weeks, family caregivers were satisfied with the program generally. In particular, family caregivers were most satisfied with materials and nurses. However, family caregivers did not have confidence in caring for the dementia patients relatively. Therefore, additional considerations for confidence improvement of caregivers were required.

Most interventions developed in Korea adopted a group session.<sup>[26,39,40]</sup> It is difficult for caregivers who care for the elderly at home to participate in a group program unless someone else takes care of the elderly person during the group session.<sup>[41-43]</sup> Actually, three of the five caregivers who applied to this program did not attend the group meetings. Accordingly, complementary ways should be considered to promote actual participation, or other approach methods need to be selected instead of a group program.

### Practice implications

In Korea, a number of the elderly with dementia in the community sector are taken care of by their family members at home because of family obligations. Caring for the elderly without professional helps requires much time and effort from caregivers due to the nature of the disease. Thus, many caregivers often experience providing care as a difficult and overwhelming task; therefore, programs for caregivers need to be developed on the basis of their needs to reduce their negative experiences and help them from becoming exhausted. Especially, an intensive and comprehensive intervention including diversified contents based on individual approaches

should be utilized in order to maximize the effectiveness of the intervention.

### 5. CONCLUSION

The aim of this study was to develop a more appropriate program than that of existing programs for family caregivers who provide care to the elderly with dementia at home in Korea. As a result, a home-based, comprehensive intervention program was developed through related literature review, validity testing, and preliminary application of the program. The program for family caregivers included 6 main concepts, 15 themes with 37 items. The six concepts were as follows: 1) emotional support, 2) knowledge improvement, 3) skills training, 4) self-care ability, 5) communication, and 6) use of resources. In addition, workbook, manuals, and semi-structured charts were developed. The period for the program implementation was six weeks including home visits, group meetings, and supportive phone calls.

However, this study has a limitation. The effectiveness of the program was not tested using the experimental research design. Thus, further studies are needed to confirm the effectiveness of developed program through the conduct of adequate and well-controlled trials. In addition, specific strategies to promote caregivers' attendance at group meetings have to be considered.

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### CONFLICTS OF INTEREST DISCLOSURE

The authors declare that they have no conflict of interest.

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