Effects of a Dementia Family Support Program on Families’ Attitude towards Dementia, Desire for Institutionalization, Caregiving Behavior and Caregiving Burden

Young-Sun Park¹, Young-Ju Jee², Sun-Hee Bae³

Abstract

The present one-group pretest-posttest pre-experimental study verified the effects of a dementia family support program on the families’ attitude towards dementia, desire for institutionalization, caregiving behavior and caregiving burden. 11 subjects, who were registered as family members of dementia patients in two dementia institutions in Gyeonggido and wanted to participate in the support program, were included in the program and surveyed from July 1 to September 30, 2016. The program was offered to the families of dementia patients for two hours weekly for six weeks and dealt with understanding dementia, self-healing, communication, living happily, living together and planning the future. The Dementia Attitudes Scale (DAS), the Desire to Institutionalization Questionnaire(DIQ), the Modified Conflict Tactics Scale for caregiving behavior, and the Short Zarit Burden Inventory(S-ZBI) for caregiving burden were used as instruments. The participants’ attitude towards dementia, caregiving behavior and caregiving burden were statistically insignificant, whereas their attitude towards and knowledge on dementia(44.73±14.56, 50.73±12.74)(t=0.65, p=.534) and total score (88.18±21.81, 92.55±16.98) negligibly increased. The physical aggression in the caregiving behavior (92.55±16.98, 1.00±1.27)(t=1.23, p=.245) and total score (4.45±2.98, 4.18±2.40)(t=0.39, p=.706) decreased. As for the caregiving burden, personal burden(16.73±6.60, 13.73±3.41), role burden(6.64±2.77, 6.09±2.84) and total score (23.36±8.61, 19.82±4.71) decreased(t=1.40, p=.193)(t=.43, p=.679)(t=.274). There was a statistically significant decrease in the desire for institutionalization (t=4.18, p=.002). These findings indicated the support program relieved the dementia families of the caregiving burden and exerted positive effects on the caregiving behavior and the attitude towards dementia of families caring for dementia patients. Also, the program decreased the desire for institutionalization of dementia patients, which in turn increased the possibility for them to live with their families at home. Hence, it is necessary to conduct further studies with larger samples so as to formulate support programs.

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for families with dementia patients and develop and reinforce the methods of implementing such programs.

Keyword : Dementia, Attitude towards dementia, Caregiving burden, Caregiving behavior, Institutionalization, Dementia families

1. Introduction

1.1 Rationale & Objective

The number of the elderly dementia patients aged 65 years and over was 540,755 in 2012, and is projected to reach approximately 2.71 million in 2050, meaning 15% of the entire elderly population will be diagnosed with dementia [5]. Approximately 2.6 million families care for dementia patients [14]. Primary caregivers of dementia patients are their children and sons or daughters in law (67.1%) and spouses (28.9%), indicating most dementia patients are cared for by their family members [15], mostly by their children or spouses [14].

Unlike the memory impairment associated with aging in general, dementia is accompanied by impairments of cognition, judgment, memory and orientation, with approximately 90% of dementia patients showing such behavioral and psychological symptoms as delusion, hallucination and anxiety [16]. Dementia is characterized by a very slow development and gradual progress, where the initial short-term memory loss is followed by abnormalities in language skills and judgement as well as other cognitive functions, which evolves to the loss of all activities of daily living and adds to the primary caregivers’ burden[17]. Families’ caregiving burden, constraints on social activities, and psychological burden increase with the severity of dementia [18], which drives them into unwanted change and serious caregiving stress [2].

While caring for dementia patients, family caregivers are subjected to emotional, psychological, physical and economic signs of burnout, feel depressed and stressed out, avoid caring for dementia patients or have conflicts with other family members [19]. Given the nature of dementia symptoms, caregivers play pivotal roles, and thus patients’ dependence on caregivers increases [20]. As primary caregivers are faced with change of their everyday living while caring for dementia patients, they develop negative emotional responses such as depression [21]. In that caregivers are affected physically and psychologically as much as dementia patients, they are called ‘hidden patients’[22]. Still, family caregivers are important on the grounds that they can delay the institutionalization of dementia patients and that they make a great economic contribution to the national health care system [1]. Therefore, it is highly important to provide the families living with dementia patients with a support program
involving counseling and education designed to relieve them of the caregiving burden and stress.

To address the challenges that families of dementia patients are faced with, the government introduced the dementia ratings in 2014 and has supported dementia patients with the long-term care service in compliance with the national long-term care insurance system for the elderly, while developing the policy for reinforcing the infra for dementia patients including medical service, care and counseling to support dementia patients and relieve the burdens of caregivers. The daytime and nighttime care is a long-term care service that ensures in-home dementia patients live with their families at home while receiving care services for a few hours at daytime and nighttime care facilities daily to help their families to have some respite from caregiving. The daytime and nighttime care facilities substantially contribute to relieving the primary caregivers of caregiving burden, while decreasing the social burden resulting from the rising health care cost for the elderly population. Largely, families rely on and are highly satisfied with the institutions taking care of dementia patients [23]. Yet, given families of dementia patients mostly lack in relevant information and knowledge about caregiving and feel psychological burdens, it is necessary to formulate some intervention programs and social support measures for family caregivers of dementia patients [3].

According to the systematic review of literature published from 1980 to 2007, intervention programs for family caregivers of dementia patients implemented some cognitive, behavioral and social coping strategies for health and challenging situations and adopted a range of methods including group therapies, counseling and phone calls, but had negligible effects in most cases [24]. An intervention program designed to help family caregivers to solve problems relevant to moderate dementia patients proved conducive to the improvement of psychological well-being but had negligible effects on relieving family caregivers of depression and reducing the institutionalization rates of dementia patients [25]. By contrast, group intervention programs partially contributed to relieving the caregiving burden and improving the coping skills, with the case management service being particularly effective [26]. A community-based respite program developed and applied to family caregivers of dementia patients exerted effects on caregiving burden, subjective well-being and social support [4].

However, reported intervention programs for families living with dementia patients focused mostly on the verification of positive effects of such programs on families. Thus, it is hard to find research on family caregivers’ change in attitude towards dementia patients, tendency towards institutionalization and change in caregiving behavior. Hence, the present paper applied a dementia family support program and verified its effects on participant families’
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attitude towards dementia, desire for institutionalization, caregiving behavior and caregiving burden.

2. Method

2.1 Design & Subjects

This one-group pretest-posttest pre-experimental research verified the effects of a dementia family support program on participants’ attitude towards dementia, desire for institutionalization, caregiving behavior and caregiving burden. 19 subjects, who were registered as families living with dementia patients in two dementia care facilities in Gyeonggido and wanted to participate in the dementia family support program, were surveyed from July 1 to September 30, 2016. The subjects were surveyed with the same instruments before and after the 6-week intervention program. In the course of the study, however, 8 dropped out of the program to take care of dementia patients or for personal causes. Hence, 11 subjects were analyzed.

2.2 Instruments

2.2.1 General information of subjects

General information of subjects included gender, age, education, relation to dementia patients, living with dementia patients, subjective health condition, and diagnosed types of dementia.

2.2.2 Dementia Attitudes Scale (DAS)

To measure the attitude towards dementia involving the dementia-related knowledge, emotion and behavior of families living with dementia patients, the Dementia Attitude Scale (DAS) developed by Carpenter[6] and used in the 2012 Dementia Prevalence Survey was used here [7]. Each question item was rated on a scale of 1-7, indicating the extent of agreement. The higher the scores, the more positive the attitude towards dementia. Question items 2, 6, 8, 9, 16 and 17 were reverse coded [35].

2.2.3 Desire to Institutionalization Questionnaire (DIQ)

To analyze the dementia burden and the desire for institutionalization, the Desire to Institutionalization Questionnaire (DIQ) developed by Morycz[12] and used in the 2012 Dementia Prevalence Survey was used here [8]. The 6 ‘Yes/No’ question items relevant to the
institutionalization showed a reliability of 0.80. ‘Yes’ scored 1, adding to a total of 6. The higher the score, the greater the desire for institutionalization [35].

2.2.4 Caregiving behavior measurement

To measure the caregiving behavior, the Modified Conflict Tactics Scale [9] was used. The Modified Conflict Tactics Scale was comprised of five items on psychological aggression and another five items on physical aggression extracted from the Conflict Tactics Scale [13] used by Beach et al. to measure the approaches to solving conflicts and evaluating potential risks [9]. If the response to at least one item is ‘Once in a while’, that suggests a clinically significant likelihood of abuse. The higher the score, the severe the abuse. The developers of this instrument reported the internal consistency was 0.69 for the elderly receiving the care and 0.67 for caregivers, each of which was based on Cronbach alpha [35].

2.2.5 Caregiving burden

To evaluate the caregiving burden of caregivers, the Short Zarit Burden Inventory (S-ZBI) [11] was used. The original version of the S-ZBI was developed by Zarit et al [10]. The S-ZBI is a shortened form consisting of 12 question items suggested by Bedard et al. Questions No.1 ~ No.9 measure caregivers’ personal psychological burden, whilst questions No. 10~12 concern the role burden. The higher the score, the heavier the burden [35].

2.3 Data Collection & Intervention Program

2.3.1 Data collection

The dementia family support program was offered weekly for 6 weeks from July 28 to October 14, 2016 at two dementia care facilities in Gyeonggido. Each session lasted for two hours. Initially, 19 subjects participated in the study but later on 8 dropped out of the program due to caregiving for dementia patients and personal causes. Subjects were surveyed before and after the program.

2.3.2 Specifics of the intervention program

The dementia family support program offered by the Korean Association for Dementia is intended to relieve families of psychological, physical and social burden associated with caregiving by providing them with the knowledge and coping skills needed to care for dementia patients. The support program was offered by an intervener weekly for 6 weeks from
July 1 to September 30, 2016 with each session lasting for 120min. The program involved understanding dementia, self-healing, communication, living happily, living together, and planning the future. Participants were presented with quizzes to review previously learned content at the start of each session. In the middle of each session, participants were encouraged to share their stories and experiences relevant to given themes for emotional support. At the end of the program, they discussed events or incidents that happened in the previous week while caring for dementia patients. The specifics of the program is outlined in Table 1.

Table 1 Composition and Content of the Dementia Family Support Program

<table>
<thead>
<tr>
<th>Warming-up</th>
<th>Program</th>
<th>Finish</th>
</tr>
</thead>
<tbody>
<tr>
<td>10min.</td>
<td>90min.(10min. including recession)</td>
<td>10min.</td>
</tr>
<tr>
<td></td>
<td>10min.</td>
<td>10min.</td>
</tr>
</tbody>
</table>

Session 1: Opening
- Understanding dementia

Session 2: Self-healing

Session 3: Communication

Session 4: Living happily

Session 5: Living together

Session 6: Planning the future

Ending

Quiz: To review previous week’s learning

Session 2: Self-healing

Session 4: Living happily

Session 5: Living together

Session 6: Planning the future

Tea time: Sharing the previous week’s happenings related to dementia care

Data analysis

Collected data was analyzed with SPSS/WIN 21.0. Subjects’ demographic data, i.e. general characteristics and education, was analyzed with descriptive statistics (real number, percentage, mean and standard deviation). The effects of the support program on subjects’ dementia attitude, desire for institutionalization, caregiving behavior and caregiving burden were verified with a paired t-test by comparing pre- and post-intervention data.

Table 2 General characteristics of subjects (N=11)

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Category</th>
<th>Frequency(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>Male</td>
<td>2(18.2)</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>9(81.8)</td>
</tr>
<tr>
<td>Age</td>
<td>50 - 59</td>
<td>2(18.2)</td>
</tr>
<tr>
<td></td>
<td>60 - 69</td>
<td>6(54.6)</td>
</tr>
</tbody>
</table>
3. Results

3.1 Subjects’ general and dementia-related characteristics

Subjects were 9 females (81.8%) and 2 males (18.2%). Subjects’ age groups included 50-59 (n=2, 18.2%), 60-69 (n=6, 54.6%) and 70 and above (n=3, 27.3%). As for education, the largest number of subjects were ‘high-school graduates’ (n=6, 54.5%) followed by ‘primary school graduates’ (n=3, 27.3%). As for the relation to dementia patients, 5 subjects were spouses (45.5%), while 3 were children (27.3%). 8 subjects were living with dementia patients (72.7%). Subjects’ subjective health conditions were ‘good’ (n=3, 27.3%), ‘average’ (n=4, 36.4%), ‘bad’ (n=2, 18.2%), and ‘very bad’ (n=2, 18.2%). As for the diagnosed types of dementia, the ‘Alzheimer type dementia’ (n=5, 45.5%) outnumbered the ‘vascular dementia’ (n=1, 9.1%) and ‘other types of dementia’ (n=2, 18.2%). 3 families (27.3%) had no idea of the type of dementia. The duration of
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dementia care included less than a year (n=2, 18.2%), 1-5 years and 5-10 years (n=3, 27.3%, each), and over 10 years (n=1, 9.1%) (Table 2).

3.2 Verifying the effects of the support program

The effects of the support program were verified by comparing the pre- and post-intervention means. Upon completion of the support program, the mean dementia attitude and knowledge (44.73±14.56, 50.73±12.74) and total (88.18±21.81, 92.55±16.98) scores slightly increased, which was statistically insignificant (t=-2.13, p=.059)(t=-1.21, p=.254). By contrast, the dementia adjustment slightly decreased from 43.45±9.91 before the intervention to 41.82±7.61 after the intervention (t=0.65, p=.534). The desire for institutionalization showed a statistically significant difference, decreasing upon completion of the support program (t=4.18, p=.002). As for the caregiving behavior, the mean physical aggression (1.73±2.10, 1.00±1.27) and total (4.45±2.98, 4.18±2.40) scores decreased, which was statistically insignificant (t=1.23, p=.245)(t=0.39, p=.7.6)[35]. The psychological aggression score was not statistically significant (t=-.71, p=.492) but increased from the pre-intervention mean 2.73±2.15 to the post-intervention mean 3.18±1.99. As for the caregiving burden, the personal burden scored 16.73±6.60 and 13.73±3.41 before and after the intervention, respectively. The role burden scored 6.64±2.77 and 6.09±2.84 before and after the intervention. The total burden scores were 23.36±8.61 and 19.82±4.71 before and after the intervention, respectively. Therefore, the personal burden, role burden and burden total scores decreased after the support program. Yet, the differences were negligible and statistically insignificant (t=1.40, p=.193)(t=.43, p=.679)(t=1.19, p=.274)(Table 3).

4. Discussion

The present study applied a support program for families living with dementia patients and verified its effects. The program proved effective in terms of the participants’ attitude towards dementia, desire for institutionalization, caregiving behavior and caregiving burden.

<table>
<thead>
<tr>
<th>Parameter on dementia</th>
<th>Domain</th>
<th>Pretest (M±SD)</th>
<th>Posttest (M±SD)</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attitude on dementia</td>
<td>Stabilization</td>
<td>43.45±9.91</td>
<td>41.82±7.61</td>
<td>0.65</td>
<td>.534</td>
</tr>
<tr>
<td></td>
<td>Knowledge</td>
<td>44.73±14.56</td>
<td>50.73±12.74</td>
<td>-2.13</td>
<td>.059</td>
</tr>
</tbody>
</table>
According to the results, the mean attitude towards dementia and knowledge increased by 6.0 after the support program, and the total score including the adjustment increased by 4.37. These results are comparable to a previous report that knowledge increased after a dementia program [27], and another report that a program helped families of dementia patients to efficiently change their roles and plan and prepare for future caregiving as needed [28]. These findings indicate dementia-related programs benefit the families caring for dementia patients. In particular, programs involving knowledge about dementia, how to cope with dementia and how to communicate with dementia patients for better understanding of dementia proved effective. In contrast, the mean dementia attitude and adjustment decreased by 1.63, which seems attributable to the unchanged outcomes in dementia patients although the families put into practice what they learned from the short-term program. This finding suggests intervention programs should offer differentiated contents and counseling activities to the families of dementia patients by taking into account the severity of the disease[35].

The Desire to Institutionalization Questionnaire (DIQ) results decreased statistically significantly. This finding parallels a previous paper on the caregiving burden of families of dementia patients abroad, which reported that diverse intervention measures including counseling, education, stress management, coping strategies and technical support significantly decreased the caregiving burden of the families caring for dementia patients, and ultimately contributed to decreasing the institutionalization and hospitalization of dementia patients [29]. The present findings indicate that the support program involving self-healing, how to live happily with dementia patients, living together with dementia patients, and future planning
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decreased the institutionalization and helped dementia patients live at home.

As for the caregiving behavior of families of dementia patients, the mean physical aggression decreased by 0.73 upon completion of the support program, and the total score including the psychological aggression decreased by 0.27. In contrast, the mean psychological aggression increased by 0.45. This finding substantiates a previous report that families of dementia patients needed customized programs designed to help them cope with not only dementia patients’ behavior but also their own emotion while caring for dementia patients, given the methods of responding to dementia patients’ symptoms are not fixed but vary with situations [30]. Also, the present finding is comparable to a report that the emotion-focused coping decreased whereas the problem-focused coping improved after an intervention program [31]. Still, considering another report that informing family caregivers of problem-solving methods could prevent or decrease the negative emotion or depression as part of an emotional readiness [32], a comparative study is needed. In that this study recruited the subjects without taking into account the stages of dementia patients they were caring for, and as a result failed to provide proper information and knowledge for the families going through some emotional confusion, further studies should develop customized intervention programs involving physical, emotional and support services in each stage of dementia [18].

As for the effects of the support program on caregiving burden, the mean personal burden decreased by 3.0, while the mean role burden and the total score decreased by 0.55 and 3.54, respectively. This finding is comparable to a report that families of dementia patients should be prepared for each different stage of dementia and that their burden varied with their readiness [33]. Also, this finding parallels another report that other family members’ cooperation could reduce the burden felt by the primary caregiver [34]. That is because the dementia-related program provides the knowledge about the progress of dementia symptoms and how to cope with them and thus helps them to play their roles well in caring for dementia patients as well as informs the families of how to get help from other family members, institutions and national systems so that they could have their own personal time and properly care for the dementia patients, relieving the caregiving burden.

5. Conclusion

The present study verified the effects of a support program for the families caring for dementia patients. The program exerted positive effects on the participants’ dementia attitude, caregiving behavior and caregiving burden. Thus, the proposed dementia family support
program could be considered as a positive intervention for family caregivers, relieving their caregiving burden. Yet, the decrease in the mean dementia attitude and adjustment should be taken into account in developing a program. The dementia family support program exerted positive effects on the desire for institutionalization, and thus seems to be an appropriate option for dementia patients to live with their families at home. The present findings need be replicated with a larger sample, and the dementia family support program should be continuously developed and reinforced.

References


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