Empowering older people with early dementia and family caregivers: A participatory action research study

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Abstract

Background: The increase in the number of people suffering from dementia is of increasing global concern. A survey on the living conditions of the elderly in a Japanese rural community revealed a high prevalence of early dementia and the necessity for interventions not only for the elderly with early dementia but also for their families.

Objective: To describe the implementation and process evaluation of a programme based on cognitive rehabilitation aimed at empowering the elderly with early dementia and education and counselling programmes aimed at likewise empowering their family caregivers.

Design: This study used a community health action research model. Participatory action research (PAR) was conducted through a cycle of planning, action, and reflection to identify effective interventions to empower participants with dementia (PsWD) and their caregivers.

Setting: A rural town in Japan.

Participants: This project involved 37 community-dwelling elderly with early or mild dementia and 31 family caregivers.

Methods: A focus group interview was used for assessment. A monthly activity-based programme based on cognitive rehabilitation was developed to improve cognitive function. Three types of data were collected: observational data collected during the activities, written comments from the caregivers, the record of phone interviews and counsellings with caregivers. These data were compiled in chronological order into a portfolio for analysis. To empower family caregivers, educational and counselling programmes were offered.

Results: The PAR lasted for 5 years and evolved over three cycles: individual, group and community. In the first cycle, the major focus of the intervention was to regain procedural skills for each PWD through a cooking programme. In the second cycle, to increase interactions with family members and with other PsWD, group activities that promoted...
communication among family members as well as among PsWD were implemented. The collective values and the beliefs of the PsWD’s generation were validated by a series of trips to temples and shrines. In the third cycle, community participation was planned and implemented through culturally relevant sequential activities. PsWD demonstrated their expert skills and regained confidence. For family caregivers, the educational programme provided knowledge about dementia and utilization of social resources. Face-to-face and phone counsellings were offered as needed to coach problem-focused coping. These programmes helped to interpret the symptoms of dementia and to reduce the behavioural problems.

**Conclusions:** Cognitive rehabilitation theory was useful to restore lost procedural skills and regain confidence for PsWD. This PAR illustrated the importance of interventions for both community dwelling elderly with early dementia and their family caregivers.

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**Keywords:** Participatory action research; Dementia; Family caregiver; Rural health services

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**What is already known about the topic?**

- Studies on interventions in very early dementia are scarce, and institutionalized elderly with advanced stages of dementia have been the major focus of dementia care research.
- Few interventions on dementia care have targeted both the elderly with dementia and their family caregivers.

**What this paper adds**

- Cognitive rehabilitation, by restoring lost procedural skills which demented persons used to like or to be good at, is an effective tool for regaining self-confidence in persons with early dementia.
- Giving positive feedback to demented persons who have lost their confidence is an important element for their empowerment.
- Education and counselling in the form of coaching are effective for family caregivers of dementia persons to cope with symptoms of dementia.

**1. Introduction**

The current increase in the number of people with dementia is of global concern, suggesting that a heavy care burden is being imposed on a large number of family members with an associated rise in cost to society for dementia care (Rimmer et al., 2005). Advanced-stage dementia has so far been the major focus of research and there are various services targeting persons with this stage dementia (Bond et al., 2005). However, research on early dementia is relatively scarce due to the difficulty in screening the disease (Cotter, 2006). Furthermore, depression in early dementia is common and has harmful effects, and thus should not be neglected (Clare et al., 2002). Interventions for dementia currently implemented include reality orientation, cognitive-behavioural interventions, exercise and validation therapies; these interventions are mostly evaluated in institutionalized persons or day-care participants. Such interventions aim to improve cognitive function, increase engagement and reduce depression in an institutionalized population (Burgener and Twigg, 2002). However, conclusive evidence for effective interventions remains to be identified.

A literature search on nursing care identified two relatively new theoretical applications for community-dwelling elderly with dementia—cognitive rehabilitation and empowerment (Ellis-Stoll and Popkess-Vawter, 1998; Katsuno, 2003; Pearce et al., 2002). For people with early dementia, cognitive rehabilitation has been proposed by clinical psychologists as an intervention; it is a concept originating from memory rehabilitation after brain injury (Clare et al., 2003). The goal of cognitive rehabilitation is to improve or maintain impaired cognitive function. People with Alzheimer’s disease have a problem in encoding and retrieving information, but not in storing it. They also face difficulties in executive function and divided attention. Various training methods and devices (Johnstone and Stonnington, 2001a) have been developed to improve these impaired functions. Following the introduction of this theory in Japan, a few pilot studies have reported positive findings such as the regaining of procedural skills (Mimura and Komatsu, 2004). Although cognitive rehabilitation experts tend to focus on a particular cognitive function, the theory could be useful within a holistic approach to improve instrumental activities of daily living, something that people with dementia tend to fail at in an early stage leading to a loss of confidence. As empowerment is considered to restore the power individuals have lost (Ellis-Stoll and Popkess-Vawter, 1998), cognitive rehabilitation could be used as a tool to regain various procedural skills they lost and so empower them.

Aside from lost skills, some studies have examined what demented persons perceive they have lost.
A prospective study of 84 pairs of patients with dementia and their family caregivers examined the meaning of the disease. They found that the patients experienced meaningful losses such as loss of meaningful past relationships, loss of positive leisure activities, and loss of control over life decisions and fear of embarrassment (Burgener and Dickerson-Putman, 1999). Identified changes in family relationships included loss of intimacy with spouses, increased supervision, and limitations imposed on activities (Burgener and Dickerson-Putman, 1999). Our study suggested the importance of the family as a unit for intervention.

In spite of the apparent increased care burden in families with demented family members, many caregivers do not use support services; mainly because of a perceived lack of need or a lack of awareness (Brodaty et al., 2005). Bond et al. (2005) conducted a survey in Europe and found that family caregivers of demented persons had insufficient information about the benefits of treatment and care. They concluded that educating the family about the disease itself is not enough, and that health care professionals need to make a concerted effort to comprehend the caregiver’s understanding of the symptoms that are manifested in dementia. Interventions for family caregivers of demented persons are mostly psychosocial interventions and respite care (Lee and Cameron, 2004; Peacock and Forbes, 2003; Schulz et al., 2002). These interventions are difficult to evaluate due to the differences in the type of interventions, outcome measures, intensity, duration of the interventions, and the heterogeneity of target populations. Although these review articles indicated promising results for some interventions, further refinements are required before they can be recommended. In summary, the interventions for family caregivers reported do not seem to meet the needs of those who have multiple problems. Furthermore, few studies on interventions have focused on community-dwelling elderly with early dementia and their family caregivers.

This paper describes the implementation and process evaluation of a group activity programme that used cognitive rehabilitation theory to empower community-dwelling elderly individuals with early dementia and education and counselling programmes aimed to likewise empower their family caregivers through action research.

2. Methods

2.1. Design

We employed a participatory action research (PAR) approach to develop a group activity programme for community-dwelling elderly individuals with early dementia and education and counselling programmes for family caregivers. The model for PAR is a community intervention model employed in the field of community health nursing; this model is used by nurses to conduct community assessments, initiate community collaborations, involve the target population, and include reflection (Kelly, 2005). The PAR evolved over three cycles; each cycle of intervention involved the use of three activities, planning, action, and reflection. We considered PAR to be one of the most appropriate methods as such a process had to be iteratively applied to develop a programme suited to the local culture and customs.

2.2. Settings

The study site was a rural town in Japan with a population of 4800, with elderly (≥65 years old) comprising 32% of the population. In the early 1990s, the local public health nurses (PHNs) conducted a survey on the living conditions of people with dementia and their families and found that some demented elderly residents were compelled to stay indoors due to their disease. The PHNs then initiated a campaign to educate town residents about dementia by conducting meetings for caregivers and organizing charity film festivals.

In 1995, the PHNs organized a study group on dementia; this group consisted of health care centre staff and university researchers. The group then held lectures on dementia throughout the town. In 1997, they conducted the first Elderly Health Survey for all elderly residents to screen persons with early dementia (Ikeda et al., 2001; Ishikawa et al., 2006) and found that the prevalence of dementia was 5% (n = 60). In 1998 the PHNs initiated various types of activities, such as dementia prevention education and mental health counselling for the elderly. The PHNs coordinated multi-disciplinary staff consisting of both practitioners and researchers. In the first cycle, the practitioner team included one social worker from the home-care support centre (the staff leader), two PHNs (certified care managers), one occupational therapist, and one care worker; the research team included one nurse researcher from a university and one psychiatrist from a university hospital. In total, six researchers and 11 practitioners participated in the PAR. The researchers participated in the activity programme as staff members.

2.3. Participants

Elderly residents diagnosed as having early or mild dementia with a Mini-Mental State Examination (MMSE) score of ≥18 and their family caregivers were recruited. Prior to enrolment, eligible persons with dementia and their caregivers were informed that they could freely access, participate in or withdraw from the research at any time. They were also informed that an
alternative service would be offered if a participant with dementia (PWD) was unable to continue group activities due to deteriorating physical and/or cognitive function. After explaining the study protocol, written informed consent from each participant and his or her family member were obtained.

In the first cycle, 24 participants with dementia (PsWD) were determined as eligible. Of those, 18 PsWD and their 14 family caregiver participants (FCPs) enrolled in the research. Six PsWD declined due to vascular dementia with severe physical disabilities, and their families preferred to utilize home-care services rather than attending the group activity sessions. Table 1 displays the demographic characteristics of the PsWD and FCPs in the three cycles. The number of PsWD and FCPs in each cycle are presented in Table 2.

2.4. Data collection and analysis

Permission to implement the programme was obtained from the executive administrator of the rural town involved, and the study was approved by the Ethical Review Board of Ehime University Medical School.

2.4.1. Problem identification and basic information gathering

A focus group interview was conducted with the family caregivers of the first cycle PsWD for problem identification (Nomura and Ohnakado, 2005). This interview focused on the following themes: (1) the daily life of the elderly individual with early dementia; (2) the problems perceived by the caregivers and their responses to the problems; (3) the neighbours’ behaviour towards PsWD; and (4) the utilization of health care resources in the town. Additional information was collected by interviewing the family caregivers to explore the PWD’s potential, including his or her life history, hobbies and areas of interests. The researchers and practitioners qualitatively analysed the interview data to identify the issues that needed to be addressed.

We abstracted information relating to the PWD’s characteristics—medical diagnosis, MMSE, place of living, family structure, living arrangement, etc.—from the elderly person’s health records.

2.4.2. Data collection and analysis

We used three data sources to monitor changes in the PWD. First, a semi-structured observation sheet was used to record the following information: (1) PWD’s

Table 1
Demographic characteristics of participants

<table>
<thead>
<tr>
<th>Elderly with early dementia (total number of participants = 37)</th>
<th>Female</th>
<th>Male</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td>26</td>
<td>11</td>
</tr>
<tr>
<td>Mean age in years</td>
<td>78.9 ± 6.0</td>
<td></td>
</tr>
<tr>
<td>Living arrangement</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Living alone</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td>Living with spouse</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>Extended family</td>
<td>15</td>
<td></td>
</tr>
<tr>
<td>Others</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Types of dementia and cognitive problems</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alzheimer’s disease</td>
<td>17</td>
<td></td>
</tr>
<tr>
<td>Cerebrovascular dementia</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Mild cognitive impairment</td>
<td>15</td>
<td></td>
</tr>
<tr>
<td>Mean MMSE* scores</td>
<td></td>
<td></td>
</tr>
<tr>
<td>At the onset of the research</td>
<td>21.8 ± 4.6</td>
<td></td>
</tr>
<tr>
<td>At the end of the research</td>
<td>19.1 ± 5.6</td>
<td></td>
</tr>
<tr>
<td>Mean number of sessions attended per participant</td>
<td>7.7 ± 9.0</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Family caregiver (total number of participants = 31)</th>
<th>Female</th>
<th>Male</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td>22</td>
<td>9</td>
</tr>
<tr>
<td>Relation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>13</td>
<td></td>
</tr>
<tr>
<td>Daughter or son</td>
<td>11</td>
<td></td>
</tr>
<tr>
<td>Daughter-in-law</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>Mean age in years</td>
<td>61.7 ± 14.9</td>
<td></td>
</tr>
<tr>
<td>Living arrangement</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Living with the participant</td>
<td>28</td>
<td></td>
</tr>
<tr>
<td>Living separately</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Occupation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Office worker</td>
<td>11</td>
<td></td>
</tr>
<tr>
<td>Farmer</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>Self-employed</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>10</td>
<td></td>
</tr>
</tbody>
</table>

*Mini-Mental State Examination.
facial expressions, behaviours and the content of their conversations; (2) staff impressions regarding the PWD during the activity; (3) the group atmosphere during the activity session. Second, a communication notebook was created to record a summary of the activity and written comments from the family caregivers regarding the PWD’s conditions and any observed changes after the group activities. The notebook was returned home with the PWD. Third, the content of the monthly phone interviews and counsellings with caregivers was recorded in a communication log sheet. The caregivers reported the PWD’s conditions as well as their own feelings and behaviour towards the PWD. If the FCP reported any problem, a counselling was offered and recorded in the log sheet. The record of face-to-face counselling was also filed in the log sheet.

A conference, attended by all staff and researchers, was held at the end of the session and used to discuss the reactions of the PsWD during the session and any changes noted from the start of participation using the three data sources. Generally 2 h were spent to discuss all the PsWD who attended the session; on average eight PsWD attended. The researcher summarized the discussion, and its content was confirmed at the next conference.

Table 2
Number of participants in the programme (July 2000–June 2005)

<table>
<thead>
<tr>
<th>Cycle</th>
<th>Duration</th>
<th>PsWD*</th>
<th>Group activities</th>
<th>Educational session</th>
<th>Counselling</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Face-to-face</td>
<td>Phone</td>
</tr>
<tr>
<td>First</td>
<td>1.5 years</td>
<td>18</td>
<td></td>
<td>8</td>
<td>6 –</td>
</tr>
<tr>
<td>Second</td>
<td>2 years</td>
<td>24</td>
<td></td>
<td>5</td>
<td>13 22</td>
</tr>
<tr>
<td>Third</td>
<td>1.5 years</td>
<td>15</td>
<td></td>
<td>–</td>
<td>5 14</td>
</tr>
</tbody>
</table>

*a Participants with dementia.

3. Results

3.1. Assessment: issue identification

Seventeen family caregivers participated in the focus group interview. To summarize the conclusions of the interview (Nomura and Ohnakado, 2005), the elderly with early dementia were thought to be withdrawn or had a reduced motivation towards life. As the disease progressed, the time the demented elderly residents spent indoors increased. The caregivers did not consider this to be a serious situation, presuming it to be one of the symptoms of aging and only sought help from care providers after their patient’s cognitive function became impaired to the extent that they could no longer communicate with their family and their relationships had collapsed.

Based on these results, the following objectives for empowerment for the PsWD were identified: (1) to regain self-confidence and (2) to improve the PWD’s relationships with their families.

3.2. Programme description for the PsWD

The monthly activity-based programme commenced in July 2000 at a centre for the elderly located in the centre of the town. The PAR evolved over three cycles: at individual, group, and community levels. In the first cycle, improving procedural skills of each PWD was a major strategy for empowering PsWD. Once it was achieved, empowering at group level was aimed by improving family relationship and fostering comraderieship among PsWD. Then, empowering at community level was sought by increasing community participation.

The programme for PsWD included health counselling and cooking activities in the morning, and various other activities were conducted in the afternoon.

3.3. Programme descriptions for FCPs

To empower FCPs, education and counselling programmes were offered. The focus group interview
identified the needs for education, and the following specific objectives were set: (1) to increase understanding of dementia, (2) to educate on the appropriate use of social resources, and (3) to create a social network for FCPs.

Counselling was offered face-to-face on request from the beginning of the PAR. Then, phone counselling was started in the second year as a part of the monthly phone interviews, and counselling was offered when a problem was identified by the FCP. The social worker or care managers, who had relevant training, were responsible for counselling. The following strategies (Watanabe, 1999) were employed in interviewing and counselling to promote problem-focused coping: (1) commendation of the caregivers’ efforts, (2) identifying and focusing on one major problem, (3) explaining reasons behind the symptom or behaviour, (4) assuring FCPs’ feelings of upset and anger as natural reactions to the symptoms, and (5) exploring specific strategies together.

3.4. Process evaluation of the activity programme for PsWD

3.4.1. First cycle: to empower at an individual level

We selected cooking as the main activity to apply cognitive rehabilitation theory (Johnstone and Stonnington, 2001b) because it is an essential daily activity and ensures the use of acquired skills in the elderly. An occupation therapist and geriatrician specialized in cognitive rehabilitation developed the basic framework for the cognitive rehabilitation-based cooking programme. Table 3 shows the specific strategies that were gradually modified to suit the PWD’s cognitive function. For example, affixing large labels to the seasoning bottles was employed in the second year when staff noticed that some PsWD had difficulty differentiating one seasoning from another. Implementing such strategies into activities required careful observation of the PsWD. The staff discreetly provided physical or verbal prompts to assist PsWD and to maintain the PWD’s pride. If a PWD was unable to remember the work sequence and stopped his or her actions, the staff quietly gave them the utensil or seasoning that was required for the next action.

The following case represents a careful assessment of a female PWD’s ability, the selection of tasks appropriate to her cognitive level and the staff’s continuous exploration of the client’s potential:

Ms. A, an 80-year-old woman with an MMSE score of 18, who had not cooked for 20 years since her daughter-in-law took over the position of homemaker, initially chose to take responsibility for arranging food items by saying ‘I cannot use a kitchen knife’. Gradually, with the staff’s assistance, she learned to divide the food evenly and arrange food items on a plate. The staff learned from the other PWD that she used to be a cook. Subsequently, she was given the opportunity to cut vegetables and soon became accustomed to this activity. After one year of participation, she successfully cleaned and sliced a 50 cm sea bream and received loud applause. From that day on, she started being an active participant in the group activities.

The PsWD were never rushed when carrying out tasks. They soon learned who was proficient at particular skills, and all regained procedural skills. They became so proficient at cooking that cooking time was reduced from 2.5 to 1.5 h by the end of the first cycle.

Afternoon activities that were designed to improve memory function mostly failed to interest the PsWD (Table 4). This was partly because staff were not acquainted with the elderly PsWD’s cultural background.

Initially, we were afraid that the PsWD and their FCPs might be stigmatized for being members of the early dementia group. To our surprise, the PsWD were proud of their group and even named it the ‘Linden Tree

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**Table 3**

<table>
<thead>
<tr>
<th>Cognitive function impaired</th>
<th>Specific strategies to compensate cognitive impairment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attention</td>
<td>Minimize distracting stimuli in the environment (e.g., noises)</td>
</tr>
<tr>
<td></td>
<td>Work in cubicles or divide the space for each task (e.g., washing, cutting, and boiling sections)</td>
</tr>
<tr>
<td>Divided attention</td>
<td>Structure activities to ensure that a participant is engaged in one activity at a time</td>
</tr>
<tr>
<td>Memory function</td>
<td>Affix a large label on bottles of seasonings</td>
</tr>
<tr>
<td>Retrieval</td>
<td>Use external memory aids (e.g., “to do” lists)</td>
</tr>
<tr>
<td></td>
<td>Environmental cues and triggers (To place kitchen utensils in a visible place)</td>
</tr>
<tr>
<td></td>
<td>Subtle physical prompts such as handing out utensils required for the next action</td>
</tr>
<tr>
<td>Executive function</td>
<td>Compartmentalize the main task into subtasks</td>
</tr>
<tr>
<td>General strategies</td>
<td>Create a routine for a specific task (e.g., use the same layout in the same place)</td>
</tr>
<tr>
<td></td>
<td>Allow extra time to complete</td>
</tr>
<tr>
<td></td>
<td>Pace yourself: Don’t take on more than you can handle</td>
</tr>
</tbody>
</table>

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Group’ by the end of the first cycle. By then, the PAR became known to the professional society of care workers as a result of a paper presentation. We received requests to observe the sessions, and permission from both PsWD and their FCPs were obtained. Contrary to our reservations, the PsWD were pleased to receive guests. The observation log sheet shows that the PsWD planned special menus, dressed up and prepared speeches for their guests.

### 3.4.2. Second cycle: to empower at a group level

As the cooking activities were successful for improving the procedural skills of the PsWD, the PAR team set up a goal to improve family relationships and group dynamics among PsWD. In addition to the communication notebook, various strategies were used to increase conversations among family members. The following vignette of Ms. A summarizes a process of regaining respect from her family members:

<table>
<thead>
<tr>
<th>Cycle</th>
<th>Focus of empowerment</th>
<th>Objectives and selected activities to improve cognitive function</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>First</td>
<td>At an individual level</td>
<td>1. Enhance explicit memories: Japanese 100 classic short poem card game (while the first half of the poem was being read, PsWD were expected to find the card with the last half of the poem on the table). 2. Enhance episodic memories: sequential activities (making pressed-flower bookmarks)</td>
<td>1. Educational background of PsWD differed and only those with higher education benefitted. PsWD with higher education enjoyed this activity “I could still recall the latter half of the poem.” PsWD with minimal education quietly left the game saying “I don’t understand”. 2. Failed to interest PsWD because the majority were not used to reading. “What’s the use?”</td>
</tr>
<tr>
<td>Second</td>
<td>At group level</td>
<td>1. Improve IADL: shopping at a “100 yen” shop 2. Improve IADL: dining out at a fast food Sushi restaurant (select menus and pay bills) 3. Recall autobiographical memories and enhance episodic memories: kite making and kite flying with the family 4. Recall autobiographical memories: tours of local temples and shrines valued by PsWD.</td>
<td>1. PsWD were empowered to carry out shopping. Even passive PsWD became animated and asked the shop clerk about the location of a specific item. They used large bills for small charges. 2. PsWD could identify all the fish and select what they liked. They used large bills for small charges. 3. Both PsWD and their family enjoyed making and flying kites together. 4. “All the villagers should sweep the garden of the shrine. It should not be neglected.” “All the villagers used to come here for flower-viewing when I was little.”</td>
</tr>
<tr>
<td>Third</td>
<td>At community level</td>
<td>1. Create an opportunity to show off their procedural skills in the community: culturally relevant sequential activities such as plum wine making. 2. Manage sales at the local festival where PsWD sold the products they made (collecting bills and giving change)</td>
<td>1. PsWD carried out all the tasks proficiently without waiting for instructions. They taught and complimented each other. “Our family does this way. How about yours?” 2. PsWD attracted customers by speaking in a clear voice and helped them to select products. With the staff’s support, they could pack the products and collect money without making errors.</td>
</tr>
</tbody>
</table>

Note. All the outdoor activities were summarized in a communication notebook with photographs attached, and the notebooks were taken back to the family in order to enhance episodic memories by creating an opportunity to talk about the day.

*aParticipants with dementia.  
bInstrumental activities of daily living.*
On the day Ms. A processed the sea bream; the leftover fish was cooked and taken back to her family. When the staff delivered her home, she talked to her-daughter-in-law about her accomplishment by handing out the communication notebook with the picture of dishes she made. In the monthly phone call, her daughter-in-law informed the researcher that she would set up an opportunity for Ms. A to display her culinary skills on special occasions. A follow-up phone interview showed that Ms. A cooked on her great-granddaughter’s birthday, and her family members started to again pay respect for Ms. A.

Cooking menus for those who were not used to cooking were explored; hand-kneaded noodles, a popular homemade regional dish, was selected. The cooking processes were compartmentalized into smaller tasks, and at the first trial the men kneaded the dough with ease. Rolled eggs were also enjoyed by men. These activities contributed to increase interactions with their families. For example, an 83-year-old male PWD, who had never cooked, offered to peel potatoes, which pleasantly surprised his wife.

For the afternoon activity programmes, we sought activities to get the family involved; thus kite making as part of a kite flying project was assigned as homework (Table 4). The conversation log sheet revealed that all the PWD and their family members enjoyed kite making, which provided a topic for further conversation. Some grandchildren asked the PWD, “Grandpa, what did you play when you were little?”

To improve instrumental activities of daily living, shopping at the “¥100 yen (0.67 Euro) shop was introduced. The PsWD, who were not trusted to shop by themselves, enthusiastically joined in at this shop which served as an errorless shopping environment (Table 4). The conversation log sheet revealed that even for those with severe short-term memory problems, this outing remained a favourite conversation topic for months among the group and within the family.

Through a series of group activities and long lunch time conversations, groups started to serve as self-help groups. The observation log sheet revealed that the PsWD freely expressed their opinions about the menus and activities and helped each other during the session. The PsWD started talking about beliefs and values on topics such as spirituality and worshipping the deities during lunch time conversations, according to the observation log sheet. Trips to temples and shrines were then implemented. These visits gave the PsWD the opportunity to share their own beliefs on the importance of worshipping ancestors with younger staff members (Table 4).

3.4.3. Third cycle: to empower at community level

Community participation by the PsWD was planned to fully utilize culturally relevant sequential activities such as plum wine-making so that they could display their expert skills in community events (Table 4). This gave the PsWD an opportunity to teach the younger staff their know-how, which in turn boosted the PsWD’ self-esteem. Some PsWD said, “Young town folks (the staff) don’t know how to select, pick, and clean plums. You have a long way to catch up with us.”

With an increase in the positive responses from the PsWD and their FCPs, the staff also became increasingly interested and enthusiastic in the activities. Selling homemade products at the local festival generated a profit, which enabled the PsWD to dine out. However, the plum wine-making project required staff to accompany the PsWD in picking, storing and managing the plums, which increased the amount of time staff had to spend on the project. Therefore, it was decided that community volunteers were necessary to sustain this level of activities.

Toward the end of the PAR, two PsWD became spokespersons for the demented participants. When a representative from the local government visited the centre, the PWD requested financial aid for purchasing cooking equipment. They also suggested that a similar programme should be started in each community so that the elderly would be able to walk into a nearby centre in their own community without depending on others for transportation.

The success of the PAR was also reflected in the number of referrals. After our programme became recognized in the town, 19 persons were referred to us.

3.5. Process evaluation of the education and counselling programmes for FCPs

Of the 31 FCPs, eight who were in the focus group interviews, enrolled in the education programme. The remaining 23 FCPs had full- or part-time employment. The numbers of FCPs who participated in each programme of the three cycles are noted in Table 2. Although the number of FCPs for the education programme was small, it achieved all three objectives. For example, the FCPs who considered dementia to be a ‘destruction of character’ gained an understanding of the PsWD’ altered behaviours and became more tolerant of them. One FCP reported that she had changed her manner of dealing with her mother-in-law, saying “I used to do things for her. Now, I try to let her do things by herself as much as possible”. Attending educational sessions offered caregivers the opportunity to share coping skills. Subsequently, a small network of caregivers was formed; however, it failed to grow. While exploring this failure, the conversation log sheet revealed that the need for a caregiver network was actually small.
Every one in a small rural community would know who had dementia, and family caregivers in the same generation in geographic proximity tended to share information and provide affective support.

The initial educational session focused on improving the knowledge of various social resources because the underutilization of such resources was thought to reflect a lack of knowledge. However, conversations with FCPs indicated that FCPs perceived that day-care services were for people at an advanced stage of dementia. As well, there was a stigma attached to the use of resources. Subsequently, a case study approach was used to illustrate the benefit of resources, which facilitated their understanding of the benefits. The conversation log sheets revealed that resistance to the use of resources slowly disappeared. In the second cycle, educational sessions were offered individually when a new PWD was referred to the PAR.

In the second cycle, monthly phone calls were initiated to gather information, to educate caregivers, and to counsel caregivers. Staff routinely asked about any changes and problems faced and allowed caregivers to talk about care burden issues. On these occasions, the staff educated the caregivers about dementia for them to understand the PWD’s behaviours and what to expect. For example, many FCPs complained that the PWD tended to lose precious items. After this behaviour was explained, a typical response was “I became upset many times as she lost very expensive things, now I understand that because it is precious to her, she tried to hide in a place where no one would look for it.”

The counselling programme aimed to coach problem-focused coping. The following case briefly describes the process of problem identification, counselling, and follow-up:

A 71-year-old homemaker with MMSE score of 18 started to participate in the PAR in the second cycle. A problem with declining activity of daily living was noted by the husband one year prior to the programme enrolment. She stopped cooking breakfast and taking care of the family Buddhist altar which had been one of her roles for the past sixty years. She used to light a candle, offer incense sticks to the altar, and to pray. Initially, she did not join the cooking activities, and in the third session, she started to use a kitchen knife. When the husband learned about her use of knife, he complained about her not cooking breakfast during the phone interview. Face-to-face counselling with the husband was conducted, and her detail life history was obtained. Discussions were focused on her procedural skills. The conversation log sheet revealed his trial and error process. First, her husband asked her to cook breakfast, which was not palatable. According to her family, cooking was not her favourite activity even before she developed dementia. Then, he prompted her to take care of the altar in the morning, which she succeeded and continued to do so. He praised her accomplishment, which he was taught through phone counsellings. She started to pay attention to grooming and started to actively participate in housekeeping and family events after six months.

Through the increased use of phone counselling, problems related to PsWD were identified at an early stage, as shown in the conversation log sheets, and the need for face-to-face counsellings gradually decreased (Table 2).

However, there were families who did not appreciate the benefits of the PAR. Those who were too busy with work/child-rearing or lived far away from the PWD failed to detect small changes in the PWD. Regardless of the FCP’s degree of participation, FCPs asked for counselling when the PWD’s psycho-behavioural symptoms worsened.

4. Discussion

The uniqueness of our PAR was the application of cognitive rehabilitation theory to regain lost procedural skills to empower PsWD. Cooking played a major role in restoring confidence in PsWD. Cooking involves many interdisciplinary factors: safety, standing, balance, fine motor coordination, memory, visual skills, problem-solving, socialization and cooperation (Johnstone and Stonnington, 2001b). If menus are carefully chosen based on the cognitive function and potential of the PsWD, cooking activities can be employed for PsWD in any culture, as shown in our male PsWD. Furthermore, our cognitive rehabilitation model could be modified for use at home to sustain cooking skills with minimal assistance from the caregiver.

Basic principles used in our activity programme are similar to the Montessori methods for persons with dementia developed by Camp et al. (1997) and Orsulic-Jeras et al. (2000). Lessons advance from the simplest to more complex ones, and materials are selected from the every day environment. Tasks are broken down into steps and then sequenced. Activities involve immediate feedback, high probability of success, and repetition. In a pilot study by Camp et al. (1997) that used the Montessori method, persons with dementia could teach children various activities and enjoyed it.

The major difference in the intervention between ours and those of other researchers (Clare et al., 2002; Orsulic-Jeras et al., 2000) is the person-centred approach integrating personal history and preferences with cognitive rehabilitation theory. Rather than just giving demented persons specific tasks to do for training, we selected culturally relevant procedural skills which the
PWD used to be good at or to be fond of. Two cases presented here demonstrated the importance of obtaining a detailed personal history of what they had been skilled at.

Intervention studies for family caregivers of demented persons tend to offer highly specific coping skills, such as anger and depression management (Coon et al., 2003) and stress management and coping skills management (Marriott et al., 2000). In our study, staff counsellors played the role of coach to assist FCPs to identify the major problem and to discuss the strategies together. “Coaches are trained to listen, to observe and to customize their approach to individual client needs. They seek to elicit solutions and strategies from the client; they believe the client is naturally creative and resourceful” (International Coach Federation, 2007). As caregivers face a variety of problems and the readiness of the caregivers for intervention differs, coaching might be preferable to a highly structured coping skills training programme (Mahoney et al., 2006). A few studies have examined the effectiveness of coaching family caregivers of demented persons (Gant et al., 2007; Hepburn et al., 2001), and evaluation of the method and content of coaching merits further exploration.

Although some studies have targeted both PsWD and family caregivers for intervention (Mahoney et al., 2006), our study demonstrates the importance of intervening with both. As both PsWD and caregivers feel the loss of the family relationship (Burgener and Dickerson-Putman, 1999), improving the family relationship itself can result in empowering both of them. The cases presented here illustrate how much family caregivers can contribute to restoring self-confidence in PsWD, which in turn improves the well-being of the caregivers.

The choice of PAR was appropriate for this research as the application and implementation of cognitive rehabilitation theory had to be tailored to the local culture and the PWD’s background. Gradually, the team members became students of the PWD to learn about the local culture. On reflection, the PAR evolved from a medical model programme based on cognitive rehabilitation to a holistic nursing model of normalization.

4.1. Implications for nursing practice

Empowerment nursing interventions are still at an experimental stage (Chenoweth and Kilstaff, 1998; Huang et al., 2003), and appropriate methods for empowerment need to be explored as they relate to each culture. Selecting activities that utilize the PWD’s remaining procedural skills and explore their potential abilities can help to increase their motivation. Obtaining a detailed life history and past activities of daily life is useful to identify the procedural skills they used to have. Our PAR suggests that the acknowledgement of the PWD’s potential by the group and by family members appears to be important for their empowerment. In addition to the use of cognitive rehabilitation components, the staff’s respectful attitude towards the PWD and faith in the potential of the elderly are essential for empowerment.

It is also essential to educate family caregivers who take care of persons with early dementia, even though they may have little care burden (Brodaty et al., 2005; Hoskins et al., 2005). Educating the family about the use of social resources (Brodaty et al., 2005) and dementia is not sufficient (Bond et al., 2005). Although our study did not offer an educational package to the family (Gitlin et al., 2005), our coaching approach was successful in improving coping skills by providing feedback to the family caregivers on professional observations, assessments, interpretations of various symptoms associated with dementia and the manner of dealing with the PWD’s cognitive decline.

Collaboration between practitioners who are familiar with the local culture and multi-disciplinary researchers is important for the continued improvement of the programme and for tailoring activities for PsWD.

4.2. Limitations of the study and future research needs

The activity-based PAR was not suited for elderly with physical disabilities. They declined to participate in the research as the cooking activity and the various outings required mobility. Therefore, it will be necessary to formulate a different programme for those with physical disabilities.

There are three areas of research that merit further exploration: the process of changes in family caregivers, in staff, and in the community. First, family caregivers were not systematically interviewed about their experience with the PAR. Caregivers’ perspectives on their experience with the PAR will be helpful to refine the programme for caregivers. Second, the experiences of the staff and researchers with the PAR also merits further research as each staff member learned about other disciplines while working in a team. Third, people in the small community became involved in the PAR by the third cycle. The group’s active participation in community events increased the visibility of the group in the community. The empowered PsWD appeared to have contributed to the destigmatization of dementia in the community. This process requires detailed exploration in future research.

4.3. Difficulties experienced in the PAR

The staff faced various difficulties during the long journey of the PAR. An initial difficulty in the implementation process was to recruit eligible persons and to explain the benefits of the research to their family caregivers. We approached a key decision-maker in the
family or influential friends of the eligible person by visiting them and sending letters to establish rapport.

Subsequently, eligible persons were requested to participate in the group activity. However, we encountered some difficulties in dealing with PsWD with aphasia and those with early onset dementia. The activity-based programme needs further refinement to accommodate these individuals.

The researchers also faced difficulties in managing multiple data sources and analysing all the data. Although a portfolio was created for each PWD, the accumulation of large amounts of data was difficult to analyse. As well, we became deeply involved in the activity programme and had considerable trouble judging the appropriate time for preparing a manuscript for publication.

It was a challenge for the researchers to permit the practitioners to take the initiative in the PAR, though we attempted to be on equal footing in the discussion. In conclusion, participation in the PAR was a deeply satisfying experience for all team members.

5. Conclusion

The PAR reported here using the cognitive rehabilitation theory was conducted to empower elderly PsWD with early dementia and their FCPs. The PAR helped these elderly PsWD to regain lost procedural skills and acquire confidence. The recognition of their skills by the group members and by their families appeared to be the most powerful component of empowerment. The education and counselling programmes for family caregivers promoted problem-focused coping skills and improved family relationships. Even though the group members changed during the 5-year period, the group gained recognition in the community due to its active participation in community events.

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