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# **Issues Based on Activities of National Dementia Supporters in Japan**

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## **Abstract**

**Introduction.** More than 13 million dementia supporters were expected to be trained in 2020. However, studies have indicated that approximately 70% of them are inactive.

**Purpose of research.** This study seeks to elucidate and address the challenges associated with dementia supporter engagement.

**Methods.** Published literature was collected by searching the web versions of the Journal of Health Care and Society from 2015 to 2021. Eleven studies met our inclusion criteria.

**Results.** The ages of the supporters ranged from teenagers to those in their 80s. The most active supporters were women in their 60s or older. Of them, 40–50% had experienced caring for family members. They received support for their jobs and housework. They primarily watched and talked to older people with dementia. Supporters had difficulty preparing meals for the recipients, shopping, and going out with them. The leading reasons for inactivity were a lack of contact with senile seniors, insufficient opportunities for support activities despite high motivation, and poor self-confidence in nursing care skills and knowledge. Supporters hoped to learn appropriate care methods to deal with the recipients' wandering, anxiety, and delusions.

**Conclusion.** Three issues emerged: women in their 60s and older played a central role in support activities, meaning that older supporters assisted older adults with dementia; limited availability of venues and the scope of activities resulted in low levels of engagement among supporters; and dementia supporters required knowledge and specialized care skills to deal with BPSD (behavioral and psychological symptoms of dementia) during supporter training.

**Keywords:** dementia, dementia supporters, Japan, supporter activities

## **I . Introduction**

The number of older individuals with dementia in Japan is estimated to reach approximately 7 million by 2025, with one in five older adults developing dementia. Therefore, the number of older adults with dementia is expected to increase. Notably, the revised Comprehensive Strategy for Promoting Dementia Measures (hereinafter referred to as the New Orange Plan), outlined in 2017, aimed to realize a society in which the wishes of people with dementia are respected, enabling these individuals to continue to live their own lives in a good environment within their familiar communities as much as possible (Ministry of Health, Labour and Welfare, 2017). One specific initiative involved the activities of dementia supporters (hereafter, supporters). In the New Orange Plan, supporters are defined as having the correct knowledge and understanding of dementia and assisting people with dementia and their families in their communities within their capabilities. Furthermore, support from community advocates contributes to an environment in which older individuals with dementia and their families can lead their daily lives with peace of mind. Specifically, in educational settings, such as schools, activities such as interactions between older individuals and children are facilitated, as are educational initiatives to deepen the understanding of prevailing conditions in an aging society. Supporters play a crucial role in advancing these activities and are thus important in Japan's dementia measures.

The government increased its target for training supporters from 8 million at the end of fiscal year 2017 to 12 million at the end of fiscal year 2020 owing to the increase in the older population. Consequently, the number of trainees reached 13.01 million by December 2020, exceeding the target number (Ministry of Health, Labour and Welfare, 2021). However, a survey by Arakawa et al. (2016) targeting supporters found that 25.9% were active and 74.1% were inactive, indicating that more than 70% of all supporters were not active. This indicates that “the increase in the number of supporters has not led to an increase in supporter activity”. While dementia supporter activities are important for spreading

understanding and support for dementia, their content and effectiveness have not been sufficiently verified.

To support older people with dementia and their families in the community, which is expected to continue to increase in the future, it is necessary to build a system in which supporters who have completed dementia-supporter training courses can participate in community activities. This study aimed to clarify the current situation regarding support activities and to examine the issues that make them more effective.

## **II. Research Purpose**

This study aimed to clarify the issues related to dementia supporter activities and obtain suggestions for future directions.

## **III. Research Method**

1. Research Design: A literature review was conducted.

2. Research Period: The research period was from May 2022 to October 2022.

3. Data Collection and Analysis Methods:

1) The selection criteria for the target papers were as follows: original papers published in *the Journal of Health Care and Society* in Japan during the 7 years from 2015 to 2021. ② The keyword “dementia supporter” was included. This study discusses the content and effectiveness of dementia support activities. Eleven studies met the inclusion criteria and were selected (Table 1).

The reason for setting the journal's publication year was set to 2015 because the New Orange Plan was formulated in 2015 and papers published thereafter were targeted.

2) Analysis Method: Issues and suggestions for dementia supporter activities were extracted from the target papers, classified, organized, and compared, and their characteristics and trends were clarified.

#### **IV. Ethical Considerations**

The terms and data used in these articles have been accurately cited. When cited, information such as the author's name and year of publication are clearly indicated in the text. To avoid violating copyrights, quotations from the literature were cited accurately, and sources were clearly indicated. In addition, when expressing opinions or judgments about the content of the cited literature, it is clear that they are those of the authors.

#### **V. Results**

##### 1. Overview of target papers

No papers were published in 2015; however, since 2016, 1–3 papers have been published each year. In terms of research methods, eight studies used questionnaire surveys, two used interview surveys, and one used other methods.

##### 2. Activity Status of Supporters

The activity status of the supporters was examined in terms of sex, age, employment status, activity content, frequency of activity, time spent on activity, and level of activity. In terms of gender, more than half of the supporters were women, and their ages ranged from teenagers to the 80s. The most active age group was over 60 years, with over 60% of the patients being over 70 years old, as shown by Teshima (2020).

By contrast, the main inactive age groups were those in their 20s and older than 80 years. In terms of employment status, 67.8% of the participants were employed, with more than 60% employed in certain occupations, as reported by Arakawa et al. (2016). The main occupation was housewives (30%), followed by part-time jobs, employees, and self-employment. In terms of activity content, community-based monitoring activities (35.3%) and listening activities (33.9%) were the most prevalent, and the venues for these activities were salons (24.2%) and dementia cafés (17.7%), as reported by Teshima (2020).

Regarding frequency and time spent on activities, the main frequency was less than twice a week (approximately 80%), as reported by Koyama et al. and Arakawa et al. In addition, it was found that approximately 80% spent more than 30 minutes on activities. From these results, it can be inferred that individuals actively spend 30–60 minutes or more on activities once a week. Furthermore, regarding the activity level, 25.9% were active and 74.1% were inactive, indicating that more than 70% were not active, as Arakawa et al. reported. The reasons for this included “not having met people with dementia”, “not having an opportunity to start activities”, “not having time to spend on activities”, and “needing to learn more as a supporter<sup>3</sup>.” In addition, Uchida et al. (2016) reported that approximately 50% of caregivers were not actively involved in their activities.

### 3. Training supporters and their roles in the community

The motivations for attending supporter training courses varied. More than half of the participants chose to attend because of their intrinsic interest, while others found encouragement from their peers (Arakawa et al., 2016; Uchida et al.; 2016).

Furthermore, the curriculum for these training courses primarily followed a standardized one, augmented by discussions on understanding and responding to dementia, delivered through lectures, dramatizations, DVD presentations, and dialogues with individuals living with dementia and their families. Insights gained from the training courses were addressed in two of the 11 reviewed studies. Specifically, according to Ohno, opinions diverged; some participants contended that the knowledge gained was useful in caring for relatives after completing the course, whereas others articulated uncertainty about the suggested course of action, resulting in limited practical involvement (Ohno, 2020). Arakawa et al. highlighted that participants apply their newly acquired knowledge by adhering to guidelines when interacting with individuals with dementia in public settings (Arakawa et al., 2016). Furthermore, efforts were made to actively engage and listen to acquaintances diagnosed with dementia. Importantly, a significant proportion (approximately 90%) of participants recognized the importance of early recognition and assimilated knowledge about adapting to the pace of people with dementia.

These results imply that a substantial number of participants enrolled in supporter training courses owing to their engagement with individuals affected by dementia, with the courses primarily emphasizing the standard curriculum. Concurrently, supporters' roles within the community include surveillance and companionship, with training providing participants with insights into dementia. Moreover, anticipation concerning the future scope of support activities was probed in a study by Koyama et al., in which 103 staff members from community-based support centres across seven cities and towns were surveyed (Koyama & Uchida, 2018).

The results showed that the main activities expected of supporters were to watch (safety confirmation),



accompany, initiate dialogue, and participate in dementia cafés. Other activities that stood out included assistance with toileting, accompanying people to outings, shopping, and meal preparation.

## **VI. Discussion**

### **1. Activities and Issues of Supporters**

Many active supporters are employed and perform their activities in parallel with their daily lives within limited frequency and time. The main activities of the supporters were watching, talking, cafés, and salons, and the places were expected to be dementia cafés and salons. However, it has been pointed out that the frequency of dementia cafés and social awareness are low (Aihara & Maeda, 2019). In addition, there are issues such as the fact that people with dementia and their families do not gather and there is a shortage of manpower (Kai & Oshima, 2021; Inn et al., 2022; Takechi, 2020). Furthermore, it is difficult for the parties and their families to grasp the existence and activities of the café because the operation and location of the café are not facilities that are used in daily life.

Moreover, according to a survey by Uchida et al., training courses were held in many municipalities in the prefecture, but follow-up courses and PR/evaluations of supporter activities were few, and supporter activities were not active (Uchida et al., 2016). Notably, the government cited a lack of understanding and manpower in dementia cafés as an issue (Dementia Policy Project Team, & Japan Health Policy Organization, 2022; Dementia Care Research and Training Sendai Center; 2019a; Dementia Care Research and Training Sendai Center; 2019b; Health and Global Policy Institute, 2021) which can be attributed to the lack of dedicated space for activities, as well as issues in identifying interactions between supporters and older people with dementia. These factors ultimately contribute to a lack of community support.

Therefore, cooperation between related organizations and residents is indispensable for promoting

support activities. Specifically, related organizations must implement PR for local residents and continue to provide places for exchange and activities. This will enable supporters to understand the needs of older people with dementia and their families and provide individual support. In addition, it is necessary to consider continuous activity support after the course.

## 2. Issues in supporter development

In training courses, the content that is immediately applicable in the field is limited, given that basic knowledge is predominantly offered in a lecture format. Therefore, it is imperative to develop supporters effectively, including practical learning experiences and fundamental knowledge and skills. Moreover, it is crucial to tailor the course content to the needs of the field by considering the perspectives of supporters and relevant stakeholders. Supporters' primary activities involved watching, talking to, and serving as conversation partners for individuals with dementia. Notably, more than 90% of participants believed they could converse with older people with dementia (Koyama & Uchida, 2018), suggesting a significant impact on their actual activities. Supporters can acquire basic knowledge and practical skills through training courses. In addition, when considering community activities, it is difficult to deal with problems, such as wandering symptoms, in people with dementia. Supporters can find reassurance in discussing concrete examples, points to be mindful of, and sharing experiences while engaging in observation and support. On the other hand, activities that supporters found difficult included preparing meals, going out together, and shopping. Thus, it is evident that supporters believe specialized basic knowledge is essential for interacting with older individuals with dementia and perceive such interactions as highly challenging. The underlying reasons may include concerns about being unable to manage if a problem arises, or reluctance to intervene without an established relationship with an older individual with dementia, given the necessity of involving themselves in someone else's domestic affairs.

Thus, beginners may commence activities aligned with their individual capabilities (Hirota & Fuchida, 2018; Ishikawa et al., 2016; Toki et al., 2017) and gradually gain experience. However, for experienced supporters, it is a challenge to present activities individually to provide more specific support according to the needs of older people with dementia and their families and encourage them to engage in activities that suit their abilities. Nevertheless, we believe that it is essential to promote the acquisition of more specific coping methods for behavioral and psychological symptoms of dementia (BPSD) during supporter development (Kume, 2023; Naka, 2023; Kimura et al., 2022). Furthermore, in the supporter development curriculum, we believe that incorporating practical skills and simulations more actively, as proposed by Uchida et al., will improve supporter activities in the community.

## **VI. Limitations and future issues of this study**

This study is a literature-based analysis, the limitations of which include the small number of target studies (11 articles) and a focus solely on domestic literature available through the web version of the Journal of Health Care and Society in Japan. Consequently, many aspects related to the activities of dementia supporters have not been adequately discussed. Nonetheless, given the anticipated increase in the number of older individuals with dementia, we believe that we have gained valuable insights into the issues surrounding the activities of dementia caregivers, who serve as crucial pillars of community-based dementia care. Importantly, future research should encompass a broader array of literature, including studies from international sources.

## **VII. Conclusion**

This study aimed to clarify the issues related to dementia supporter activities. We targeted 11 articles related to the purpose of this study, grasped the current situation of dementia supporter activities, and discussed related issues based on them. Consequently, three issues were identified: First, the center of the activity involves women in their 60s and older, and it is the older supporters who assist the older individuals with dementia. Second, the location and content of the activities were limited, meaning that supporters were not fully utilized. Third, it is essential to encourage the acquisition of specific coping methods for individuals with BPSD to develop support. Specifically, we propose the development of training courses and materials that suit the abilities and needs of supporters and suggest courses that include practical skill acquisition and lectures, as they constitute integral components for the growth and effectiveness of dementia supporters' activities.

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Uchida, Y., Ide, N., Koyama, A. et al. (2016). Facts and future concerns about dementia supporter activities—On the basis of survey data obtained in Gunma Prefecture. *Annals of Gunma University Graduate School of Health Sciences*, 37, 63–68.

**Table 1 List of Target papers**

No.	Authors	Year	Journal	Title	Research Purpose
1	Miyano K, Oyama H, Kashiwaba H, et al.	2021	Journal of Japan Academy of Human Care Science, 14(1),16-24	The Reality and Direction of Support for "Confused Experiences" Encountered by Newspaper Carriers Engaged with Elderly Suspected of Dementia	Clarify the "Confused Experiences" encountered by newspaper carriers supporting individuals suspected of dementia in the course of their work.
2	Teshima H.	2020	Humanity and science. Journal of the Faculty of Health and Welfare, Prefectural University of Hiroshima, 20(1),45-61	Future development of Dementia Supporters Program and community activities—For the formation of a community that embraces people with dementia	Understand the elements of the developmental expansion of the dementia support course through a program that links participation in the course to community activities supporting individuals with dementia.
3	Ohno H.	2020	Bulletin of Toyohashi Sozo University, 24:11-24	Survey on the Actual Activities of Dementia Supporter Training Course Completers— What Should Future Training Programs Be Like	Examine the actual post-training activities of graduates of dementia support courses to consider the future direction of dementia support training.
4	Aihara Y, Maeda K.	2019	Journal of Health and Welfare Statistics, 66(2),20-25	Current situation and issues of volunteer activities in dementia cafes in Hyogo Prefecture	Verify the characteristics and challenges of volunteer activities at dementia cafes in Hyogo Prefecture.
5	Hirota Y, Fuchida E.	2018	Japan Society of Nursing and Health Care, 20(2),25-36	Factors necessary for dementia supporters to continue their activities	Investigate the factors necessary for the continued activities of dementia supporters at an active support center in City A.
6	Koyama A, Uchida Y.	2018	Journal of Japanese Society for Dementia Care, 17(2):431-440	Investigation of dementia supporters' activities in Gunma Prefecture—Through questionnaire surveys with dementia supporters and employees of Comprehensive Community Support Centers	Clarify the activities that dementia supporters believe they can engage in and the activities expected by community comprehensive support center staff, and obtain suggestions for activity support for dementia supporters.



No.	Authors	Year	Journal	Title	Research Purpose
7	Kojo S, Kinoshita K, Okamoto S, Tada M.	2017	Japanese Journal of International Nursing Care Research,, 16(2):63-72	Activities and Future Issues of Registered Dementia Caravan Mates—By comparing two cities with a different supporter rate	The study clarifies the activities and awareness of dementia caravan mates in a mountainous depopulated area, comparing their activities with those in two cities with differing supporter-to- population ratios.
8	Toki H, Asakura R, Kunikata H, Nakamura M.	2017	Journal of Shikoku public health society, 62(1),109-113	Local residents' awareness of wandering of persons with dementia and their choice of response when they find them —From a simplified questionnaire to local residents in District B, City A	Obtain suggestions for creating a community where individuals with dementia can continue to live safely by clarifying the awareness of local residents regarding wandering and their response choices when an individual with dementia wanders.
9	Uchida Y, Ide N, Koyama A, et al.	2016	Annals of Gunma University Graduate School of Health Sciences, 37:63-68	Facts and future concerns about dementia supporter activities—On the basis of survey data obtained in Gunma Prefecture.	Clarify the training and activity support situations of dementia supporters for all 35 cities and towns in Gunma Prefecture.
10	Arakawa H, Morizane S, Kumakura N, et al.	2016	Journal of Japanese Society for Dementia Care, 15(3),634-646	Motives of dementia supporters Who attended the training session, and resolution of Issues in order to empower them in supporting people with dementia in their community	Investigate the actual activities, desires for activities, and reasons for not being active among dementia support course graduates and clarify the support issues for empowering community activities of these graduates.
11	Ishikawa K, Sakanoue I, Oya N, Kaitaya Y, Nakamura S, Taniguchi E.	2016	Journal of Osaka Kawasaki Rehabilitation University, 10,51-58	Dementia initiatives in the Kaizuka Yamate area—results of a questionnaire survey of local elderly people and our university students	Examine the current situation in the Kaizuka Yamate region, based on interviews with staff at the community comprehensive support center, questionnaire results from the elderly, and questionnaire results from university students who attended dementia support courses.