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Effects of the Participation and Involvement of Medical Professionals in Dementia Cafés on the Attendance of People with Dementia Living at Home and Their Family Caregivers

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Abstract.
Background: Dementia cafés have been attracting attention as a new approach to dementia care, but the effects of the participation of medical professionals remain unclear.
Objective: To clarify the significance of collaboration between medical professionals and dementia cafés.
Methods: Questionnaires regarding the numbers of staff and guests, whether medical professionals introduced guests, whether cafés announced their activities to medical institutions, and whether people with dementia played a role were sent to dementia cafés throughout Japan. The responding dementia cafés were then divided into two groups according to the presence or involvement of medical professionals and institutions and compared.
Results: Responses were received from 148 dementia cafés, among which, medical professionals participated in 96 (64.9%). Significantly more people with dementia living at home attended cafés run or staffed with medical professionals ($p = 0.021$ and $p = 0.017$, respectively), as well as when medical professionals introduced guests to the café or when the café announced their activities to medical institutions ($p = 0.001$ and $p = 0.002$, respectively). Significantly more people with dementia played a role in cafés where medical professionals were administrators or staff ($p = 0.008$ and $p = 0.018$, respectively). Similar effects were observed for family caregivers.
Conclusion: The participation and involvement of medical professionals and institutions in dementia cafés increased the attendance of people with dementia, especially those living at home. These results suggest that dementia cafés are an effective hub for connecting care for dementia with medical care, and thus help avoid fragmentation in dementia care.

Keywords: Caregiver, community network, dementia, psychosocial intervention, social support

INTRODUCTION

As of 2012, the number of people with dementia in Japan was estimated to be 4.62 million, which accounts for one out of every seven older people, and this number is expected to continue increasing until at least 2025 [1]. As of 2015, it was estimated that

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the number of people with dementia worldwide was 46.8 million [2]. Dementia causes a decline in cognitive function, which leads to a decline in the ability to perform activities of daily living, thereby threatening autonomous living. In addition, dementia is said to place a heavy burden of care on family caregivers [3]. These difficulties faced by people with dementia and their families also tend to cause stigma, which is another barrier to living with dementia [4].

As a way to address these issues, there is a growing trend to establish dementia cafés in the community as places where people with dementia, their families, community members, and professionals can gather to discuss dementia and share their experiences casually [5–11]. In the Netherlands, a pioneer of dementia cafés, the Alzheimer's Café was launched in 1997, and since that time, has expanded nationwide [5]. In Japan, the establishment of dementia cafés has been recommended as part of the national dementia policy, and by the end of fiscal 2018, there were reportedly about 7,000 cafés nationwide (about one per 20,000 people) [12]. At present, dementia cafés in Japan do not have clear standards regarding the frequency of meetings, staff composition, training requirements for the staff, locations, and management entities. The advantage of this is that it allows for a high degree of flexibility and diversity in the cafés. This may also make dementia cafés in Japan more attractive and lead to an increase in terms of numbers. On the other hand, as a disadvantage, it remains unclear what functions dementia cafés have, what effects are expected from their existence, and what kind of financial support is appropriate for policymakers.

In such a situation, it is important to verify the effectiveness of dementia cafés, but as a preparatory step, it is first necessary to define how dementia cafés should be operated, i.e., their frequency, programs, staff composition, staff qualifications, and relationships with local social resources. Previous studies have compiled information on the implementation of 1,335 cafés in Japan, which has started to provide insights into the most effective types of implementation and operations [12]. In addition, the creation of self-assessment forms has led to discussions regarding what skills are required for dementia café staff [13].

However, many issues regarding the management and significance of dementia cafés still need to be addressed. First, the conditions of people with dementia vary, from the mild stage, in which people can live relatively independently, to the severe stage, in which people must live with care services. It remains, however, unclear under which conditions people with dementia attend dementia cafés from the viewpoint of independence in daily life or nursing care usage. It is also important to clarify the relationship between the attendance of people with dementia and involvement of medical professionals as dementia café administrators or staff. Second, it is assumed that many people with dementia who attend dementia cafés are in the early stages of the disease, and in such cases, it is desirable that medical professionals refer people with dementia to a nearby dementia café as a form of post-diagnostic support. However, it remains unclear whether medical professionals are actually referring people to dementia cafés. Third, while many dementia cafés are run by local residents and people in the care and welfare fields, it remains unclear to what extent these cafés collaborate with medical institutions, e.g., by introducing themselves using flyers. Fourth, when people in the early stages of dementia participate in a dementia café, it seems desirable for them to play an active role, but the actual situation also remains unclear. Given this background, this study aimed to gain a better understanding of these issues and to analyze the role played by medical professionals in particular. By clarifying these situations, we hope to propose a more desirable way of managing dementia cafés. In addition, active collaboration of stakeholders through dementia cafés would help avoid fragmentation of dementia care in the community, which is a serious challenge in the field [14–16]. Therefore, if involvement of medical professionals has a positive effect on dementia cafés, it would be important to discuss the significance of their role in strengthening integrated dementia care in the community.

MATERIALS AND METHODS

Participants

In this study, we sought the cooperation of café administrators in five regions and groups throughout Japan, because it is assumed that the operation of dementia cafés has regional characteristics based on several factors, such as population density and the involvement of local municipalities. In total, 54 dementia cafés in Nagoya City, a metropolitan area, 15 in Yokkaichi City, a city with many urban areas, 47 and 97 in Kyoto and Okayama Prefectures, respectively, prefectures that include both urban and suburban areas, and 39 subsidized by the Asahi Newspaper Welfare and Culture Foundation,

which are distributed throughout Japan, were invited by post (one questionnaire was sent to each café) to participate in this study. One response written by a representative or as a consensus of the management group was obtained from each café. From among the 254 dementia cafés invited, responses were received from 166 (response rate: 65.4%). Among the responses, those from 148 cafés were considered valid and subjected to analysis. This study was approved by the Ethics Committee of Fujita Medical School (HM19–336). Written informed consent was obtained from all respondents.

Questionnaire

The first item included in the questionnaire regarded the basic operation of the café: the length of time the café has been in operation, the frequency, hours, and program of café meetings, and the numbers of guests and staff. Guests were divided into people with dementia, their families, and local residents. People with dementia were further divided into those living in institutions and those living at home, and those living at home were divided into those using or not using nursing care services. Next, we asked whether a medical professional was acting as an administrator of the café or as staff, whether medical professionals had introduced guests to the café, and whether the dementia café had announced their activities to medical institutions. Here, medical institutions were defined as hospitals, clinics, dentists, pharmacies, visiting nurse stations, and others.

Analysis

For a basic analysis, descriptive statistics were used to show the total number and percentage (%). Chi-squared analysis was conducted to assess differences in participation by occupation for the breakdown of medical personnel. We divided the guests into two groups according to the presence or absence of medical personnel. The Mann–Whitney U test was used to compare the two groups. Differences between the two groups in terms of whether people with dementia played a role in the café were compared using χ^2 analysis. The groups were also classified according to whether they had referrals from medical professionals or announced their activities to medical institutions through flyers, and then compared using the Mann–Whitney U test and χ^2 analyses to test for differences with regard to the number of guests. In this study, several issues were investigated together. However, they are independent issues in principle; therefore, we did not apply corrections for multiple testing among issues during analysis. For each issue, we planned and investigated the relationship between dementia café attendance by people with dementia living at home and the involvement of medical professionals or medical institutions as the primary outcome. The relationship between dementia café attendance by family caregivers and people with dementia having an active role in dementia cafés was the secondary outcome of this study. The level of significance was set at 0.05. IBM SPSS Statistics for Windows software version 27 (IBM, Armonk, NY, USA). was used for all statistical analyses.

RESULTS

Individual cafés were most frequently held once a month for 2 hours. The most frequent café program was a scheduled combination of a short educational lecture, music, and café time. Programs involving recreational events with café time and free café conversations loosely organized by the staff (no fixed schedule) were followed (Table 1). In total, people with dementia played a role in 25 cafés (16.9%) (Table 1). An average of 4.9 staff and 16.6 guests were at each meeting.

Among medical professionals participating as café administrators, nurses were the most common (46.6%), followed by public health nurses, physicians, rehabilitation therapists, and pharmacists, with some overlap in individual cafés (Table 2). Similar results were found for the number of medical professionals participating as staff on the day of the café (Table 2). Proportions of participation of nurses were statistically higher among medical personnel as both administrators and staff ($p = 0.01$ and $p = 0.01$, respectively). Medical professionals had introduced guests to 54 cafés (36.5%), with physicians being the most common referrers. In addition, 78 cafés (52.7%) had announced their activities to medical institutions or provided information about the café (Table 2).

A comparison of the total number of staff and guests to the café and the number of people in the community, family caregivers, and people with dementia who visited the café based on whether the café was run with medical professionals revealed that the number of people with dementia living at home was significantly higher in cafés where medical professionals participated as administrators ($p = 0.021$), as was the attendance of family members of people with dementia ($p = 0.016$), as shown in Table 3A. In

Table 1
Characteristics of the participants in dementia cafés in this study

Characteristics	n	%
Period from starting café		
< 24 months	32	21.8
24–35 months	51	34.5
36–48 months	26	17.6
> 48 months	29	19.6
Unanswered	10	6.8
Sum	148	100
Frequency of meetings		
< Once every 1 month	12	8.1
1 time a month	99	66.9
2 times a month	21	14.2
Weekly	9	6.1
> 8 times a month	7	4.7
Sum	148	100
Meeting time		
< 120 min	30	20.3
120 min	88	59.5
150–180 min	16	10.8
240–300 min	12	8.1
> 300 min	2	1.4
Sum	148	100
Café program		
Free conversation	27	18.2
Scheduled combination	53	35.8
Recreational event with café time	38	25.7
Others	30	20.3
Sum	148	100
Active involvement of people with dementia		
Yes	25	16.9
No	123	83.1
Sum	148	100

Table 2
Participation and involvement of medical professionals and institutions

A. Participation of medical professionals as café administrators	No	Yes	Yes (%)
Any medical professional	52	96	64.9
Physician	129	19	12.8
Nurse	79	69	46.6
Public health nurse	123	25	16.9
Pharmacist	139	9	6.1
Therapist	130	18	12.2
B. Participation of medical professionals as café staff	**No**	**Yes**	**Yes (%)**
Any medical professional	61	87	58.8
Physician	138	10	6.8
Nurse	82	66	44.6
Public health nurse	126	22	14.9
Pharmacist	140	8	5.4
Therapist	128	20	13.5
C. Existence of medical professionals referring guests to the café	**No**	**Yes**	**Yes (%)**
Any medical professional	94	54	36.5
Physician	115	33	22.3
Nurse	129	19	12.8
Public health nurse	134	14	9.5
Pharmacist	142	6	4.1
Therapist	143	5	3.4
D. Existence of cafés announcing their activities to medical institutions	**No**	**Yes**	**Yes (%)**
Any medical facility	70	78	52.7
Hospital	86	62	41.9
Clinic	63	85	57.4
Dentist office	139	9	6.1
Pharmacy	97	51	34.5
Visiting nurse station	134	14	9.5
Others	142	6	4.1

addition, in such cafés, the number of people who participated and played a role was significantly higher ($p = 0.008$), as shown in Table 3A. The same trend was observed when medical professionals participated as staff on the day of the meeting (Table 3B).

The number of dementia cafés attended by people living at home was also significantly higher when associated with a referral to the café from a medical professional ($p < 0.001$), and among these, both those who used nursing care insurance services and those who did not use nursing care insurance services were significantly higher ($p = 0.005$ and $p = 0.005$, respectively), as shown in Table 4A. The same result was obtained when the café announced its activities to medical institutions through flyers. In this case, the attendance of family members of people with dementia was also significantly higher ($p = 0.016$), as shown in Table 4B.

DISCUSSION

Dementia cafés are expected to have a multifunctional role in providing psychological and educational support and raising awareness about dementia. In this study, we analyzed the current situation regarding dementia cafés with a focus on the relationship between the attendance of guests and the involvement of medical professionals. The results revealed that medical professionals participated as administrators or staff on the day of the meeting in about two thirds of the cafés. Nurses were the most common medical professionals involved in the café. In about one third of the cafés, the medical professionals had introduced the guests. About half of the cafés had announced their activities to medical institutions. When medical professionals were involved as administrators or staff on the day of the meeting, attendance by people with dementia who are suspected of being in an earlier stage of the disease than those using care services or living in care institutions was significantly higher [17, 18], and significantly more people

Table 3
Effects of the participation of medical professionals on dementia cafés

A. Effects of the participation of medical professionals as café administrators	Medical professionals		
	No ($n=52$) Mean ± SD	Yes ($n=96$) Mean ± SD	p
Numbers of staff and guests			
Café staff	4.5 ± 2.9	6.6 ± 5.8	0.005
Café guests	14.1 ± 8.4	18.0 ± 12.5	0.091
People in the community	9.1 ± 7.3	11.0 ± 11.4	0.795
Family member of a person with dementia	1.4 ± 1.5	2.4 ± 2.7	0.016
People with dementia	3.5 ± 4.3	4.7 ± 4.8	0.044
Living in an institution	1.3 ± 3.8	1.3 ± 3.4	0.614
Living at home	2.2 ± 2.7	3.3 ± 3.5	0.021
Living at home using care services	1.4 ± 1.9	2.2 ± 2.9	0.065
Living at home not using care services	0.8 ± 1.6	1.1 ± 1.6	0.116
Active involvement of people with dementia (%)	5.8	22.9	0.008

B. Effects of the participation of medical professionals as café staff	Medical professionals		
	No ($n=61$) Mean ± SD	Yes ($n=87$) Mean ± SD	p
Numbers of staff and guests			
Café staff	4.3 ± 2.5	6.9 ± 6.1	< 0.001
Café guests	13.6 ± 8.3	18.8 ± 12.7	0.011
People in the community	8.6 ± 7.1	11.5 ± 11.8	0.286
Family member of a person with dementia	1.3 ± 1.4	2.6 ± 2.8	0.002
People with dementia	3.7 ± 4.5	4.7 ± 4.8	0.036
Living in an institution	1.5 ± 3.9	1.2 ± 3.3	0.602
Living at home	2.2 ± 2.6	3.4 ± 3.7	0.017
Living at home using care services	1.4 ± 2.9	2.2 ± 3.9	0.06
Living at home not using care services	0.8 ± 1.4	1.2 ± 1.7	0.056
Active involvement of people with dementia (%)	8.2	23	0.018

The Mann–Whitney test was used to compare the two groups, except for the comparison of active involvement of people with dementia, where χ^2 analysis was used.

with dementia played a role. Introducing guests to dementia cafés from medical institutions and making announcements to medical institutions using flyers also had an impact on the number of guests attending dementia cafés. To our knowledge, no previous studies have investigated the involvement of medical professionals or medical institutions in dementia cafés. The results of this study all together revealed that involvement of medical professionals or medical institutions enhanced the attendance of people with dementia living at home and their family caregivers in dementia cafés, and also enhanced the active participation of people with dementia in such cafés. These enhancements will help to increase the significance of dementia cafés in the community.

Dementia cafés are held in the Netherlands, the United Kingdom, and many other countries around the world [5–9, 12, 19–23]. They are expected to serve as a place where people with dementia can express themselves, where families of people with dementia can receive psychological support, and where peer support for people with dementia and their family caregivers can be provided [7, 9, 10, 12, 21, 23]. In addition, participation in a dementia café is thought to reduce stigma against dementia and promote understanding of the disease through interactions among people with dementia, their families, local residents, and medical and nursing professionals [5, 12]. However, although dementia cafés are positioned as a way to deepen understanding of the disease and provide post-diagnosis support, the involvement of medical professionals has not been clarified. In addition to the psychological issues faced by people with dementia and family caregivers, it is also important to provide medical support for cognitive dysfunction, coping methods, symptom relief through medication, and coping with the associated decline in the ability to carry out activities of daily living. It is also important to build a cooperative system between medical institutions, medical professionals, and care professionals in terms of providing post-diagnosis support. For this reason, it is desirable for medical professionals to provide information on the use of social systems and resources, as well as advice on when and where

Table 4
Effects of the interaction between dementia cafés and medical professionals on dementia café

A. Effects of the existence of medical professionals referring guests to the café	Medical professionals		
	No ($n=54$) Mean ± SD	Yes ($n=93$) Mean ± SD	p
Numbers of staff and guests			
Café staff	5.1 ± 4.3	7.1 ± 6.1	0.016
Café guests	15.2 ± 10.9	19.0 ± 12.0	0.038
People in the community	9.7 ± 10.0	11.3 ± 10.7	0.348
Family member of a person with dementia	1.7 ± 1.7	2.6 ± 3.2	0.126
People with dementia	3.8 ± 4.5	5.1 ± 4.9	0.028
Living in institution	1.6 ± 4.0	0.9 ± 2.6	0.907
Living at home	2.2 ± 2.3	4.3 ± 4.2	< 0.001
Living at home using care services	1.4 ± 2.1	2.7 ± 3.3	0.005
Living at home not using care services	0.7 ± 1.2	1.5 ± 2.1	0.005
Active involvement of people with dementia (%)	15.1	20.4	0.408

B. Effects of the existence of cafés announcing their activities to medical institutions	Medical professionals		
	No ($n=70$) Mean ± SD	Yes ($n=78$) Mean ± SD	p
Numbers of staff and guests			
Café staff	4.6 ± 2.4	7.0 ± 6.4	0.007
Café guests	15.2 ± 9.2	17.9 ± 12.9	0.281
People in the community	9.9 ± 7.9	10.6 ± 11.9	0.568
Family member of a person with dementia	1.5 ± 1.5	2.5 ± 2.9	0.016
People with dementia	3.7 ± 4.5	4.8 ± 4.7	0.052
Living in institution	1.6 ± 4.1	1.1 ± 3.0	0.412
Living at home	2.1 ± 2.4	3.7 ± 3.8	0.002
Living at home using care services	1.3 ± 1.8	2.5 ± 3.1	0.014
Living at home not using care services	0.8 ± 1.6	1.2 ± 1.6	0.007
Active involvement of people with dementia (%)	11.4	21.8	0.093

The Mann–Whitney test was used to compare the two groups, except for the comparison of active involvement of people with dementia, where χ^2 analysis was used.

to go for consultations, which may have led to the significance of the involvement of medical professionals in dementia cafés seen in this study. On the other hand, for medical professionals, participating in dementia cafés as administrators or staff to get closer to the living situations of people with dementia and their family caregivers might be meaningful for their learning and experience [10].

While the importance of collaboration to establish integrated dementia care is self-evident, a lack of coordination, often referred to as fragmentation, has repeatedly been pointed out. Fragmentation has an impact on all aspects of dementia care, such as the development of care pathways, post-diagnosis support, the use of community resources, emergency care, and end-of-life care [14–16, 24–28]. This is typically a consequence of the field of dementia care, which involves a large number of medical, nursing, social welfare, and administrative professionals, many of whom have different educational backgrounds and professional training [29]. It can be said that the existence of fragmentation has been a barrier to improving care for people with dementia. The results of this study indicate the significance of the involvement of medical professionals in dementia cafés and demonstrate the potential of dementia cafés to function as hubs that promote collaboration among professionals, volunteers, and local residents in dementia care. In addition, these findings suggest better ways to manage dementia cafés by clarifying the current status and significance of the staff composition and the mutual relationship between cafés and medical institutions. The number of people with dementia is expected to increase in the future, and as a result, dementia care will impose a serious burden on the national economy [30–32]. Improved collaboration among the stakeholders involved could be expected to improve the quality of life of people with dementia while simultaneously controlling costs. With regard to overcoming fragmentation in dementia care, there are reports on the establishment of a community resource coordination system by specialist nurses, development of a dementia-friendly community, the use of a new quality indicator as a cue

to raise awareness of fragmentation, and the application of an interdisciplinary team approach for people with dementia who do not visit a hospital of their own accord [33–36]. It is hoped that adding such efforts toward multidisciplinary collaboration in dementia cafés will help overcome fragmentation.

This study had several limitations. First, although this research focused on the involvement of medical professionals, it did not examine the significance of the involvement of professionals in care fields such as social workers, care workers, and care managers. In the future, it will be important to examine the roles played by those other than medical professionals. Second, this cross-sectional study examined the significance of the involvement of medical professionals by using indicators such as whether the attendance of people with dementia who were not using nursing care services increased. Further studies are needed to assess longitudinal changes in the quality of life of people with dementia and their family caregivers. Third, dementia cafés are not the only community resource for dementia care, and the situation regarding community resources varies by region and country. The extent to which the results of this study can be useful as general knowledge will need to be examined in different regions and countries to improve the generalization of our findings.

Conclusion

In this study, it was revealed that the involvement of medical professionals is significant for the activities of dementia cafés, thereby suggesting that medical professionals acting as administrators, staff, and people who refer people with dementia to the cafés could make dementia cafés more effective in providing post-diagnosis support. The announcement form dementia café to the medical institutions could be also recommended. In addition, it is expected that the involvement of medical professionals in dementia cafés would help avoid fragmentation in dementia care.

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