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ORIGINAL ARTICLE

Survey on the current situation for early diagnosis of dementia and contributing factors in Japan

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Abstract

Background: Early diagnosis of dementia is important for both initiation of non-pharmacological activities to slow cognitive decline as well as the development of disease-modifying drugs; however, it appears there may be a tendency for formal diagnosis to be delayed. Since the current status of diagnosis in Japan is unclear, we conducted a survey with family caregivers of patients with dementia using questionnaires and interviews to investigate the factors regarding the dementia diagnosis process in Japan.

Methods: We distributed questionnaires to family caregivers of people with dementia and conducted additional follow-up interviews with approximately half of them. We calculated odds ratios for the time to diagnosis using logistic regression analysis for each characteristic from the questionnaire data. We also created co-occurrence networks from the interview data in order to provide qualitative context to the questionnaire data.

Results: We collected 68 questionnaires and conducted 32 interviews. The median time to diagnosis was 12 months, and logistic regression analysis showed a significant trend toward shorter time to diagnosis in the absence of other caregivers. In addition, there were significant differences in age, relationship with patients and the time from the first visit to the final diagnosis between groups with and without other caregivers.

Conclusions: The results of this study suggest that the presence or absence of other caregivers may affect caregivers' behaviour and the time taken to receive a diagnosis of dementia. These findings indicate it may be beneficial to predict inhibiting factors and change approaches based on caregivers' and patients' background to promote early diagnosis.

Key words: *dementia, early diagnosis, family caregiver.*

INTRODUCTION

Dementia is a neurodegenerative condition caused by several diseases such as Alzheimer's disease (AD) and is characterised by progressive cognitive decline and impairment of the ability to perform activities of daily living. With the ageing population, the number of people with dementia is increasing worldwide every year and was estimated to exceed 50 million by 2019.[1] Japan has one of the most rapidly ageing societies in the world with approximately 4 million people with dementia which is predicted to rise to over 5 million by 2050.[1] Dementia causes difficulties in maintaining usual life activities and a decline in quality of life for both patients and their families as well as increasing their own and societal economic burden. Therefore, the establishment of effective prevention and treatment strategies for dementia are major healthcare needs throughout the world.

Recently there has been a breakthrough in the development of disease-modifying drugs and the first drug has now been approved for use in both the US and Japan. While the long-term clinical effectiveness and safety of these new drugs remain to be established, their use is likely to be restricted to people at the earliest stages of dementia and require a diagnosis of AD.[2] Aside from drug treatment, non-pharmacological interventions which have the potential to delay cognitive decline and other symptoms of dementia should also be started as early as possible for all people with dementia.[3] In addition, early diagnosis allows the patients and their families time to discuss and prepare for the future, including making appropriate financial and legal arrangements.[4] For these reasons, it is important to promote medical examinations to detect dementia at earlier stages of the disease onset. At the same time, most of the general public would like to be diagnosed as early as possible in relation to themselves, while there is a declining trend in relation to their spouses, but overall, the demand for early diagnosis of dementia is increasing.[5,6]

Currently, the diagnosis and subsequent use of services in relation to dementia tend to be generally delayed.[7] A 2019 European survey of caregivers' views reported that only half of caregivers said they had made timely progress in diagnosing dementia.[8] Factors affecting the time to diagnosis of dementia and use of services include the following: socioeconomic reasons such as low education and low income; the severity of the condition and the burden of care; beliefs including stigma, family responsibility, and misperception as normal ageing; and knowledge of dementia and previous experience related to consultations and service use.[9] In addition, region and race have also been reported to influence the behaviours regarding the diagnosis of dementia, and accessibility to health care and being a minority in a country are also relevant.[7,10]

In Japan, there are systems in place to facilitate public access to health care and long-term care, and in recent years moves have been made to promote the building of a dementia-friendly society in which it is easier for people to live with dementia. The Framework for Promoting Dementia Care was announced in 2019 with the themes of inclusion and risk reduction,[11] and the Basic Act for Dementia to Promote the Creation of an Inclusive Society was approved on June, 2023.[12] Inclusion refers to creating an environment where people with dementia can spend their daily lives without barriers and anxiety, and risk reduction refers to delaying the onset of dementia or slowing its progression even if it does occur.[11] In anticipation of an increase in the number of elderly people and dementia patients in the future, systems to promote early detection of dementia are being established in various parts of Japan. In Kobe City, Hyogo Prefecture, citizens aged 65 or older can take a screening test free of charge and, if necessary, receive a full examination at a specialised medical institution as part of the 'Kobe Model' program.[13] In a recent example, a survey of members of the Association of People with Dementia and their Families in 2013 revealed that it takes a mean of 15 months from the first notice of changes to the final diagnosis and that over 30% of respondents said it was too long for a diagnosis.[14] Although the importance of early diagnosis has become well known and many efforts have been made, few studies have clarified the latest situation in Japan, including whether these systems are being used. Therefore, it is necessary to accurately evaluate the current situation in Japan, including the time to diagnosis of dementia, considering the recent initiatives.

This study aimed to clarify the current status leading up to the diagnosis of dementia in Kobe City and surrounding areas and to identify factors that promote or hinder diagnosis by conducting a survey of family caregivers of patients with dementia using a questionnaire and follow-up interview.

METHODS

Study design

This study was conducted in an explanatory sequential design in which quantitative data from self-administered questionnaires were complemented by qualitative data from follow-up interviews.

Participants

We recruited participants from hospitals and clinics where the authors worked and family associations in Hyogo Prefecture. The eligibility criteria for questionnaire respondents were: (1) they were family members of patients with dementia; (2) they had experience caring for them; and (3) they knew the sequence of events leading up to the diagnosis of dementia. The exclusion criteria were: (1) the participants themselves had cognitive decline; (2) they were unable to speak Japanese; and (3) they were unable to understand explanations or survey content due to impaired hearing or vision. Interview participants were selected from those who answered the questionnaire.

Data collection

We distributed the questionnaire after a brief oral explanation and participants mailed it back to us. We included an interview invitation at the end of the questionnaires, and those who agreed to participate in the interview wrote their name and contact details on that page, while those who did not were left blank. After collecting the questionnaires, we made appointments with those who agreed to participate in additional interviews, and we interviewed each of them later. On the day of the interviews, we provided written and oral explanations and obtained their informed consents. The data collection period was from February 2022 to March 2023.

Measurements

The following information about the participants and patients with dementia was obtained from the questionnaire: participants' demographics including age, sex, place of residence, and family type; relationship to the patient; care status; whether there were other caregivers, such as other family members, relatives or friends (the presence of other caregivers); name of diagnosed disease (diagnosis name); whether and what type of services were used; the time from the first notice to the final diagnosis; dementia-related knowledge; and attitudes toward dementia. We developed questions according to the following four landmarks to examine the time to diagnosis in dementia: the first noticing of symptoms, recognising obvious problems, going to doctors or healthcare providers, and receiving a final diagnosis.[9] We then calculated the time based on the responses in data obtained from each of the following questions: 'When did you first notice changes in the person?', 'When did you first visit medical institutions or consult professionals?', and 'When did you receive the final diagnosis?'

We used the dementia-related knowledge scale developed by Mikami et al. to assess behavioural and psychological symptoms and caring methods.[15] The scale has been validated in Japan and consists of 10 items with higher scores indicating more knowledge.

Attitudes toward dementia was measured using the attitudes toward dementia scale developed by Kim et al.[16] The scale consists of 15 items, with higher scores indicating more positive attitudes toward people with dementia. This scale is significantly positively correlated to the knowledge scale used in this study.[15]

The interviews were conducted as semi-structured retrospective interviews based on their responses to the questionnaire, and we asked the participants about the detailed history and time from the first notice of changes to the final diagnosis, their use of services and effects on their lives including after the diagnosis, and their thoughts about their current situation and future. For example, for the first notice, we asked questions such as 'What changes did you see in the patient?', 'What did you think at that time?', and 'What action did you take in response to those changes?' We recorded the audio of the interviews with the participants' permission and then manually transcribed them. It took approximately 10 min to explain and obtain informed consent and 1–2 h for the interview.

Data analysis

Quantitative analysis

We performed a logistic regression analysis to identify factors predicting the time to diagnosis. We divided the total time to diagnosis at the median as the objective variable, with zero for 12 months or less and one for 13 months or more. We first carried out a single regression analysis with each variable as an explanatory variable. We then performed multiple regression analysis with all variables added, the explanatory variables being age, sex (male or female), care status (now or past), the relationship to the patient (parent or others), knowledge scale, attitude scale, use of services (yes or no), disease (AD or others) and the presence of other caregivers (yes or no). We also calculated the area under the ROC (receiver operating characteristic) curve to determine each model system. The ROC curve was drawn by varying the cut-off value of the predictive score calculated when performing logistic regression analysis and plotting the sensitivity and specificity at that time.

We compared each variable in two groups based on the variables extracted as significant factors in the logistic regression analysis. For each participant's characteristics, categorical variables were compared with Fisher's exact test and continuous variables were compared with the *t*-test or Mann–Whitney *U*-test after checking for normality.

All *P*-values were two-sided, and *P*-values of 0.05 or less were considered statistically significant. All statistical analyses were performed using EZR version 2.8-0 (Saitama Medical Centre, Jichi Medical University, Saitama, Japan).[17]

Qualitative analysis

We used the KH Coder (version 3. Beta. 07) to analyze the interview data; KH Coder is a free software for quantitative content analysis and text mining of text data and is widely used for analysis in Japanese.[18,19] Co-occurrence networks are traditionally used in content analysis to statistically represent data, and KH Coder allows words that tend to be used together to be connected in a network and visualised in a diagram.[18] When creating co-occurrence networks, priority is given to those with stronger co-occurrence relationships based on the Jaccard coefficient, the number of sentences containing both words divided by the number of sentences containing one of the words. In the diagram, the size of the circle indicates the frequency of occurrence of the word in all sentences and the thickness of the line between the circles indicates that the words were used together more frequently, represented by the Jaccard coefficient.[18] In this analysis, several word groups that are strongly connected are automatically detected.[18] We created co-occurrence networks for each of three types of data: one that included all words in the interview data and one that was divided into two groups based on the presence of other caregivers. In this analysis, the minimum number of occurrences was set to 250 when all words were included in the selection, 125 when the selection was divided into two groups according to the presence of other caregivers, and 60 for the narrowing of co-occurrence relationships to be drawn.

Table 1 Respective characteristics of caregivers and patients

Variables	All sample ($n = 68$)
Caregivers	
Age, mean (SD)	66.8 (10.8)
Sex, *n* (%)	
Female	52 (76.5)
Male	16 (23.5)
Care status, *n* (%)	
Now	40 (58.8)
Past	26 (38.2)
NA	2 (2.90)
The relationship to the patient, *n* (%)	
Parents	21 (30.9)
Spouses	43 (63.2)
Siblings	4 (5.90)
Knowledge scale, median (IQR)	9.0 (8.0–10)
Attitude scale, mean (SD)	46.9 (5.47)
Patients	
The time from first notice to first visit, median (IQR)	5.0 (1.0–12)
The time from first visit to diagnosis, median (IQR)	2.0 (0.0–16)
The total time to diagnosis, median (IQR)	12.0 (1.0–12)
Diagnosis name, *n* (%)	
AD	38 (55.9)
DLB	7 (10.3)
VaD	2 (2.94)
FTD	4 (5.88)
MCI	5 (7.35)
Other	4 (5.88)
Unclear	8 (11.8)
Use of service, *n* (%)	
Yes	62 (91.2)
No	6 (8.80)
The presence of other caregivers, *n* (%)	
Yes	31 (45.6)
No	37 (54.4)

Abbreviations: AD, Alzheimer's disease; DLB, dementia with Lewy bodies; FTD, frontotemporal dementia; IQR, interquartile range; MCI, mild cognitive impairment; SD, standard deviation; VaD, vascular dementia.

Ethics

This study was approved by the Health Sciences Ethics Committee of Kobe University Graduate School (No.1061).

RESULTS

Participant characteristics

Sixty-seven of the 80 individuals responded to the questionnaire (response rate 84%), including one participant who answered for two cases, meaning a total of 68 diagnosis cases were included. Of the 67 respondents, 31 (covering 32 cases) were interviewed. The mean time for the interview was 99.5 min (SD 19.4).

The characteristics of the participants are shown in Table 1. The mean age was 66.8 years, and the majority were female. The relationship to the patient was 63% spouse and 31% parent. Most of them were currently caring for a person with dementia (58.8%), and nearly half of them said yes to the presence of other caregivers (45.6%). AD accounted for

56% of the patients' diagnoses, while nearly 12% of the participants reported that the name of the disease at diagnosis was not specified. The median time from the first notice to the first visit, time from the first visit to the final diagnosis, and total time to diagnosis were 5 months, 2 months, and 12 months, respectively. The total time ranged from a minimum of less than 1 month to a maximum of 137 months.

Factors affecting the time to diagnosis and the influence of the presence of others

The results of the logistic regression analysis with the time to diagnosis as the objective variable are shown in Table 2. In single regression analysis, the absence of other caregivers reduced the odds ratio to 0.309 ($P = 0.0263$). Other variables were not significantly different in a single regression analysis. In multiple regression analysis, the odds ratio for the absence of others was 0.237, even when other variables were added, indicating that the presence of others still had a significant effect ($P = 0.0268$). The goodness of fit was 0.639 and 0.726 from the ROC curve, respectively.

When we compared each variable between the two groups based on the presence or absence of other caregivers, we found that with the presence of other caregivers, participants were younger ($P = 0.014$), had lower percentage of spouses in relationship to the patient ($P = 0.010$), and there was a longer time from the first visit to the final diagnosis ($P = 0.030$). When we compared the two groups according to the presence or absence of other caregivers to determine whether the total time to diagnosis was within 12 months, we found that the time was significantly longer in the presence of other caregivers ($P = 0.028$). These results are shown in Table 3.

Co-occurrence networks of interview data

Figures 1–3 show the co-occurrence networks created respectively. Overall, five groups of word themes were extracted: (1) personal feelings such as 'oneself', 'think', 'know', and so forth; (2) medical appointments such as 'go', 'hospital', 'doctor in charge.', and so forth; (3) medical treatment such as 'medicine' and 'take'; (4) communication such as 'talk' and 'listen'; and (5) diagnostic procedure such as 'diagnosis' and 'receive' (Fig. 1).

In the presence of other caregivers, group (3) words 'medicine' and 'take' did not appear, and two new word groups were extracted: (6) go home such as 'home' and 'go back'; and (7) troubles such as 'most' and 'difficult' (Fig. 2).

In the absence of other caregivers, in addition to groups (1) to (5), two new word groups were extracted: (8) patients such as 'dementia' and 'person'; and (9) go home such as 'home', 'go in', and 'go back' (Fig. 3).

In the interviews, the effects and types of medicines were often mentioned, but there were also several cases in which the participant was seen for the purpose of prescribing medicines, as in 'We went to the hospital with the aim of getting him prescribed medicine, as we had done a lot of research and thought that his symptoms could be controlled with medicine' (by a respondent in 40s, female, presence of other caregivers). Regarding other caregivers, the presence of family members, as in 'If the need arises, my daughter will deal with it … I am not worried in that respect' (by a respondent in 80s, male, presence

Table 2 Logistic regression analysis with the time to diagnosis as the objective variable

	Variables (reference level)	Odds ratio (95% CI)	*P*-value	ROC (95% CI)
Single regression	The presence of other caregivers (yes)	0.309 (0.110, 0.871)	0.0263	0.639 (0.523, 0.755)
Multiple regression	The presence of other caregivers (yes)	0.237 (0.0664, 0.848)	0.0268	0.726 (0.601, 0.852)
	Age	0.940 (0.863, 1.02)	0.154	
	Sex (male)	1.39 (0.350, 5.50)	0.640	
	Care status (now)	1.12 (0.366, 3.45)	0.840	
	The relationship to the patient (parent)	3.48 (0.571, 21.2)	0.176	
	Knowledge scale	1.00 (0.724, 1.38)	1.00	
	Attitude scale	1.07 (0.947, 1.21)	0.278	
	Use of services (no)	1.49 (0.112, 19.9)	0.762	
	Disease, AD or others (others)	0.871 (0.257, 2.95)	0.824	

Note: The total time to diagnosis was divided at the median as the objective variable, with zero for 12 months or less and one for 13 months or more.
Abbreviations: AD, Alzheimer's disease; CI, confidence interval; ROC, receiver operating characteristic.

Table 3 Comparison of each variable according to the presence or absence of other caregivers

	The presence of other caregivers ($n = 31$)	The absence of other caregivers ($n = 37$)	*P*-value
Age, mean (SD)	63.3 (12.8)	69.7 (7.89)	0.014
Sex, *n*			0.78
Female	23	29	
Male	8	8	
Care status, *n*			1.0
Now	18	22	
Past	11	15	
NA	2	0	
The relationship to the patient, *n*			0.010
Parents	15	6	
Spouses	15	28	
Siblings	1	3	
Knowledge scale, median (IQR)	9.0 (8.0, 9.0)	9.0 (8.0, 10)	0.10
Attitude scale, mean (SD)	47.6 (5.95)	46.4 (5.06)	0.36
Use of services, *n*			0.40
Yes	27	35	
No	4	2	
The time from first notice to first visit, median (IQR)	5.5 (0.75, 23)	4.5 (2.0, 9.0)	0.47
The time from first visit to diagnosis, median (IQR)	4.5 (2.0, 16)	1.0 (0.0, 7.0)	0.030
The total time to diagnosis, median (IQR)	25 (10, 40)	9.5 (5.0, 22)	0.083
The total time to diagnosis, *n*			0.028
≤12 month	8	20	
>12 month	22	17	
Diagnosis name, *n*			0.80
AD	17	21	
DLB	4	3	
VaD	0	2	
FTD	1	3	
MCI	2	3	
Others	2	2	
Unclear	5	3	

Abbreviations: AD, Alzheimer's disease; DLB, dementia with Lewy bodies; FTD, frontotemporal dementia; IQR, interquartile range; MCI, mild cognitive impairment; SD, standard deviation; VaD, vascular dementia.

of other caregivers) and 'It is possible to look after the patient in a large family, but not on a one-to-one basis' (by a respondent in 60s, male, absence of other caregivers), was mentioned as a reassurance and a reduced burden. On the other hand, there were also several comments such as 'These procedures are very difficult without the understanding of the family' (by a respondent in 50s, female, presence of other caregivers), 'My father did not want to believe me about my mother's condition; it was a shock. It is very difficult to accept because they are family members' (by a respondent in 50s, female, presence of other caregivers) and 'I thought that my mother-in-law should use the services provided by the long-term care insurance, but both my father-in-law and my husband were reluctant to do so, so it kept getting delayed' (by a respondent in 50s, female, presence of other caregivers) where there were delays in asking for help due to differences of opinion with family members.

DISCUSSION

In this study, we focused on investigating the current status in Japan of the period leading up to the diagnosis of dementia and identifying factors that promote or hinder diagnosis.

The median time from the first notice of changes to the final diagnosis for the study participants was 12 months. In previous studies, the mean time to diagnosis was reported as 15 months in a 2013 Japanese survey,[14] 3.8 years in the same year in one European country,[20] and 2.1 years in five European countries in 2019.[8] In comparison, the mean time to

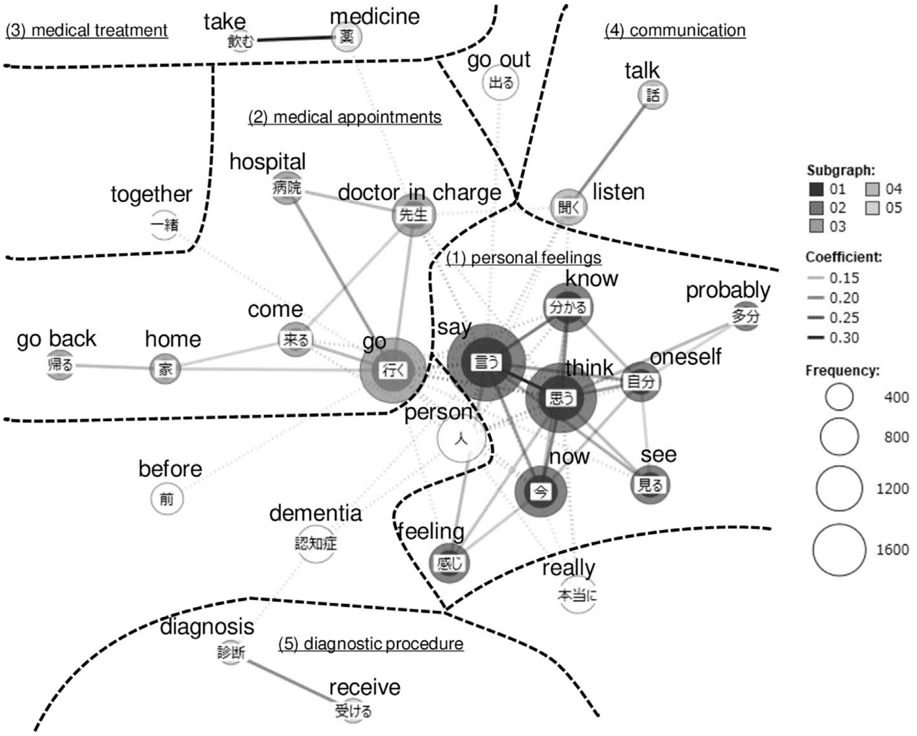

Figure 1 Co-occurrence network including all words. Frequency is the occurrence of the word in all sentences and coefficient is the frequency with which connected words occur together. In this figure, the minimum number of times the word appears in all sentences is set to 250 and the minimum number of times the word appears in a co-occurrence relationship is set to 60.

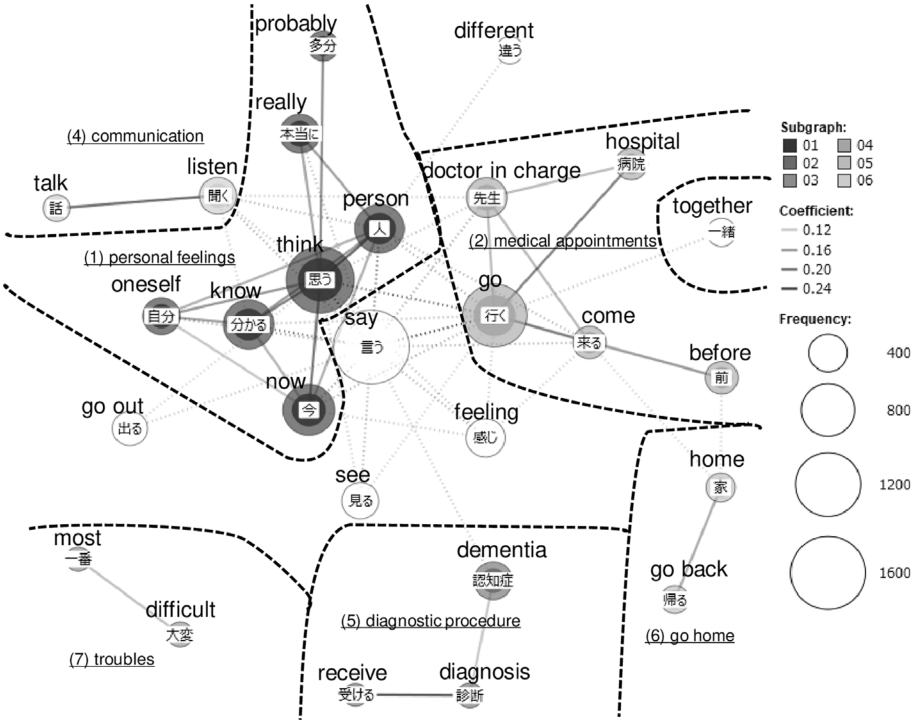

Figure 2 Co-occurrence network in the presence of other caregivers. Frequency is the occurrence of the word in all sentences and coefficient is the frequency with which connected words occur together. In this figure, the minimum number of times the word appears in all sentences is set to 125 and the minimum number of times the word appears in a co-occurrence relationship is set to 60.

diagnosis in the present study is relatively shorter which may reflect progress in the understanding of dementia diagnosis and the development of the support environment as well as increased accessibility of medical and long-term care over the last 10 years. On the other hand, the time to diagnosis

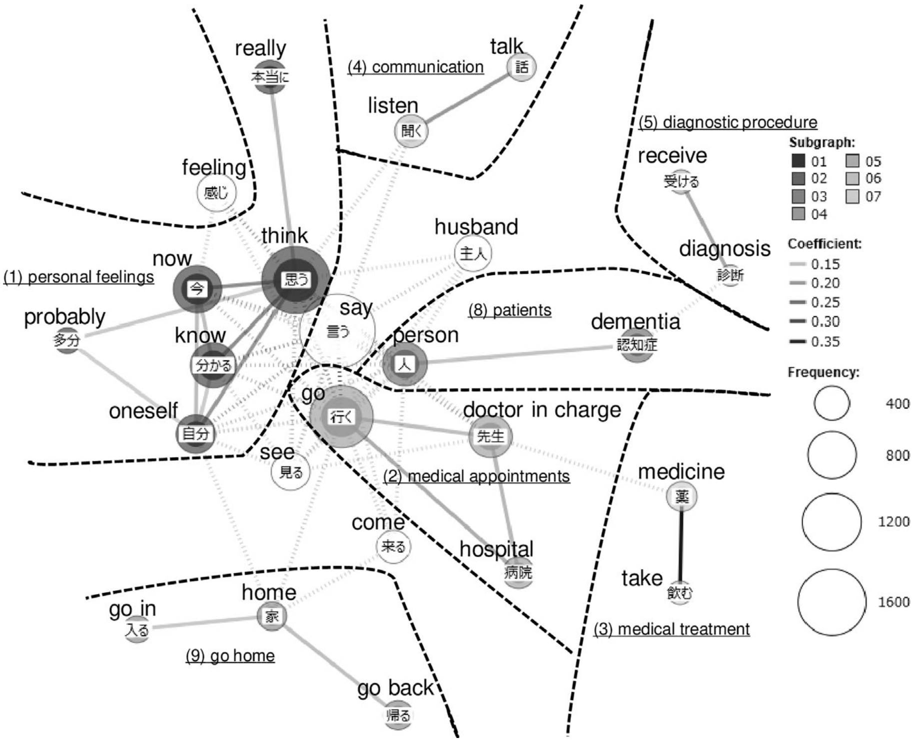

Figure 3 Co-occurrence network in the absence of other caregivers. Frequency is the occurrence of the word in all sentences and coefficient is the frequency with which connected words occur together. In this figure, the minimum number of times the word appears in all sentences is set to 125 and the minimum number of times the word appears in a co-occurrence relationship is set to 60.

varies widely, with almost half of the cases taking longer than 12 months, so it cannot be said that progress to diagnosis is smooth in Japan.

Logistic regression analysis revealed that the absence of other caregivers may be associated with a shorter time to diagnosis. In the absence of other caregivers, the mean age of the caregivers was higher and a higher proportion of them were the patients' spouses. Also, the words 'medicine' and 'take' were extracted from the co-occurrence network for all words and the absence of other caregivers but not in the co-occurrence network for the presence of other caregivers. The narratives from the interviews suggested that the presence of other caregivers, especially family members, may lead to a sense of security and reduced burden. From these facts, it can be assumed that this requires a visit to a hospital for a prescription of medicine to the patient with dementia, to lighten the symptoms and care burden as there is no other caregiver. A previous study has shown a tendency for family caregivers' interest in using services to increase as patients' symptoms progress, for example, by decreasing the amount of time that patients can be safely left alone.[21] In addition, closer family members, such as spouses and children, are likely to be the first choice for asking for help, followed by the family physician.[11] These suggest that caregivers have a greater urgency to ask for help when a patient's symptoms progress to the point where medication is required, and that the absence of other family members to consult may lead to specific actions such as visiting medical institutions or consult professionals at an earlier stage. On the other hand, the presence of other caregivers is likely to increase the chances of requesting informal help from other family members before using formal services. As a result, it can be assumed that consultation and diagnosis take longer but are smoother when it comes to receiving help from others. However, it has also been pointed out that family members can delay diagnosis by hesitating or opposing consultations due to social stigma,[22] suggesting that family members have no small influence on the need for and process of those behaviours.

There are multiple limitations to this study. First, the sample size is small and second, participants were recruited from medical institutions and family associations related to the authors, which may have introduced selection bias. This may include the possibility that one of the authors, being a doctor at a university hospital, may have prioritised participants seeking an early diagnosis. Third, the retrospective and cross-sectional survey does not ensure sufficient accuracy of the information, and the characteristics of the caregivers and patients may not be consistent with those of the time. Of these, knowledge and attitudes toward dementia do not reflect their situation at the start. Apart from that, it has been reported that structured interviews are more consistent with medical records than questionnaires in retrospective surveys,[23] and the accuracy of information may be slightly lower for participants who only responded to questionnaires than for those who were interviewed in the present study. Fourth, in Japan, accessibility to medical institutions and specialists varies by region, and we conducted this study among the residents of Hyogo Prefecture where it is relatively easy to obtain the necessary consultation and treatment for dementia. Therefore, the results obtained about the current situation regarding the diagnosis obtained in this study may not be generalisable to other less metropolitan regions in Japan. Lastly, the KH Coder utilised for qualitative analysis has the ability to analyze word and sentence structure but is not adept at scrutinising content. The use of interview data to supplement the questionnaire in this study was not enough for in-depth content analysis and individual background scrutiny. In view of these limitations, we intend to expand the sampling and add further expert thematic analysis of qualitative data to learn more about diverse and complex issues.

Despite the above limitations, this study is one of the few that reflects the current situation of progress in dementia-related initiatives and suggests that the factors required to achieve an early diagnosis need to be adapted to caregivers' backgrounds. There is a common need to disseminate knowledge about the early stages of dementia and to provide immediate support for service use and patient care after diagnosis. If there are other caregivers, it is important to provide them with individual support tailored to their needs and to inform them of the burdens and disadvantages of caring for a family member alone. If there are no other caregivers, it is important to increase the number of people they can talk to at any time and to create an environment where they can leave the patient so that they do not have to spend too much one-to-one time with them. Above all, it was suggested that it is necessary to encourage people to think that it is important for both caregivers and patients to ask for help from their surroundings, and not to hold it as an individual or family responsibility.

CONCLUSION

In this study, we conducted a survey using questionnaires and follow-up interviews with family caregivers of people with dementia to obtain quantitative and qualitative information regarding the time to diagnosis and its contributing factors. The results indicated that the presence or absence of other caregivers may be an important factor that influences the behaviour and the time taken to obtain a diagnosis. It is necessary to conduct similar studies with more participants in other regions in Japan to confirm whether these findings can be generalised and require changes in approaches to promote early diagnosis based on the background factors of family caregivers and patients.

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DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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