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## Characteristics of informal support sought by family caregivers for different types of care: A comparison between dementia care and physical care

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### Summary

This study aimed to provide an overview of the need for informal support among family caregivers who provide dementia care or physical care at home and examine the characteristics of informal support sought by them for the different types of care. We conducted a questionnaire survey across all households in Town A in northern Japan. The survey covered the level of care burden, the status of care cooperators and mutual help from community members, and the support sought from community members. Fifty participants were included in the final analysis, including 23 caregivers of people with dementia (dementia care) and 27 caregivers of people with physical disabilities (physical care). The level of care burden was mild overall, but found to be significantly higher in caregivers of dementia care compared to physical care. Family members provided the most cooperation for both types of care, and community members provided less support. Approximately 90% of the respondents answered that they need to connect with local residents and help each other, but approximately 80% answered that there is nothing that they want help with. Specific support requested from community members included "watching over" and "talking to the care recipient" for dementia care and "transportation by car" for physical care. Our analysis points to the phenomenon that caregivers were reserved and ashamed of receiving informal support from community members. Therefore, it is necessary to create a system whereby community members can actively provide caregivers for people with dementia and physical disabilities with the specific support required, as identified in this study.

**Keywords:** Informal caregiving, Family caregivers, Dementia care, Physical care

## Introduction

In Japan, more than 6.6 million people required nursing care or support under the long-term care insurance system in 2019, an increase of more than 1.6 million from 2010 (1). The most common cause of requiring care was dementia (17.6 %), followed by cerebrovascular disease (16.1%), senility (12.8%), and bone fracture (12.5 %) (2). Thus, the main types of care provided in Japan can be categorized as care for people with reduced cognitive function due to dementia (dementia care) and care for people with reduced physical function due to cerebrovascular disease, senility, or fracture (physical care). As the number of people requiring care increases, the number of family members providing care (caregivers) is also likely to increase.

Thus, it is necessary to focus on improving the quality of life of these family caregivers and to support both the care recipient and the family caregiver so that they can lead their lives with peace of mind (3). The support system for people who require care in Japan is well established, with medical and long-term care insurance services providing formal support. A study (4) has shown that formal support alone does not meet the needs of caregivers and those who need care, and that they tend to seek informal support, especially for unmet needs in psychosocial care. Therefore, it is important to provide a combination of formal and informal support (4). Therefore, the current status of informal support that has not been officially institutionalized, such as family members, local residents, and volunteers, was outlined. A study (5) that focused on dementia care reported that family members were responsible for most of the informal support, with only approximately 30% using informal

support outside the family. However, the Japanese government's dementia policy (6) promotes the strengthening of local support systems by building support teams led by local residents, so that people with dementia can continue living in their familiar communities. A study (7) has also shown the importance of helping older people with dementia and their families to obtain informal support from community members and acquaintances in order for them to continue living at home. Utilizing informal support is a flexible way to respond to individual needs (8) while maintaining ties with the community (7).

However, compared to formal support, research is scant on informal support. Furthermore, studies on informal support focusing on dementia care have not identified the informal support needed from the perspective of family caregivers, either because the survey was conducted on caregivers (5) or because the specific support was not identified, even if the target population was people with dementia and their families (9). In addition, we did not find any studies that focused on physical care.

According to a previous study (10), dementia care reported greater caregiver burden than physical care. This suggests that the informal support required for dementia care and physical care could be different.

Therefore, the purpose of this study was to provide an overview of the need for informal support among family caregivers who provide dementia care or physical care at home in Japan and examine the characteristics of informal support sought by them for the different types of care. We believe that informal support based on the type of care will reduce the burden of care on family caregivers and help the care recipient

and family caregivers continue to live in their familiar community.

## Methods

### 1. Research design

This was a quantitative descriptive study.

### 2. Research period

November 2020 to December 2020

### 3. Participants

We conducted a questionnaire survey across all households in Town A, a rural area in northern Japan. As of 2020, Town A had a population of around 11,000, with about 5,600 households and an aging rate of 40.2%. The aging rate in Japan in 2020 was 28.4% (11). This questionnaire was designed to identify the actual situation of caregivers in the community and their need for support. Of all the questionnaires distributed, 209 respondents answered that they cared for a family member or someone close to them. From these, 70 individuals were selected as dementia caregivers if the family caregivers selected only "dementia" as the disease or disability status of the care recipient and as physical caregivers if they selected only "physical disability." After those with missing values in age, gender, and care burden scale, and those who showed outliers in the care burden scale (outlier detection method using interquartile range [IQR]) were excluded, 50 respondents (valid response rate: 23.9%) were included in the final analysis.

### 4. Data collection

First, we explained the purpose, significance, and methods of the research to the mayor of Town A in writing and orally and obtained his approval. Next, we obtained the address and name of the head of the household from the Basic Resident Ledger and mailed the questionnaire to all the households. One

person from each household was requested to respond to the survey, and the forms were returned by mail.

### 5. Survey items

The items in this survey were developed based on items from a survey conducted by Carers Japan in Town A in 2015 (12). The main content of the survey consisted of 100 items, which included basic attributes, the status of community ties and support activities, whether or not they had experience in caregiving, the status of those who required care, the status of the caregivers themselves, and the support they sought.

In this research, we targeted 15 items, including six items on the "basic attributes," two items on the "use of formal support," one item on the "level of care burden," and six items on the "status of informal support in the community."

The basic attributes included the gender, age, relationship, and duration of care of the family caregivers, and the gender and age of the care recipients.

The use of formal support was defined as the type of service used, and the contact points could be trusted and consulted regarding their care.

The short version of the Japanese version of the Zarit Caregiver Burden Interview (J-ZBI\_8) was used to measure the level of care burden. The participants answered the J-ZBI\_8, an eight-question scale on subjective caregiving burden, and rated their responses on a 5-point Likert scale, which ranged from 1 (*always*) to 5 (*never*). The total score of the eight questions ranged from 0 to 32 points, and the reliability and validity of this scale were previously verified (13,14). The J-ZBI\_8 was constructed using two factors (14). The first factor, personal strain, measured the degree of negative feelings toward the situation that required care and consisted of five

questions with a total score of 0–20. The second factor, role strain, measured the degree to which caregiving interfered with the caregiver's social life and consisted of three questions with a total score of 0–12.

In addition, the following items were requested regarding the status of informal support in the community. Respondents were asked to choose from the following three options regarding the presence or absence of those who cooperated with caregivers in providing care (hereafter referred to as "caregiver cooperators"): "there is someone who cooperates frequently," "there is someone who cooperates occasionally," and "there is no one." Multiple answers were provided regarding the relationship of the caregivers from 10 alternatives. The presence or absence of community members who supported them was selected as "yes" or "no." The necessity of connecting with community members and helping each other was assessed on a four-point scale: "necessary," "somewhat necessary," "not so necessary," and "not necessary." The respondents were asked to choose between "yes" and "no" as to whether or not they actually wanted community members to help them. The caregivers were also asked to select five things they particularly wanted the community members to help them with from a list of 14 alternatives.

## 6. Data analysis

The caregivers were divided into two groups based on the type of care: a dementia care group and a physical care group. For each item of "basic attributes," "use of formal support," and "status of informal support in the community," simple tabulations were performed. The J-ZBI\_8 was analyzed using a Mann-Whitney U test between the two groups based on type of care. The significance

level was set at 5%. IBM SPSS Statistics version 27 was used for all analyses.

## 7. Ethical considerations

The questionnaire was mailed unsigned, accompanied by an explanatory note that stated the purpose of the study, the voluntary nature of the survey cooperation, and the protection of privacy. Consent was obtained by filling in the consent check boxes on the survey form and returning it. The study was conducted with the approval of the Ethics Committee of Hokkaido University of Science (Approval No. 512, date of approval: October 13, 2020).

## Results

### 1. Overview of the participants (Table 1)

Of the 50 participants, 23 were in the dementia care group and 27 were in the physical care group. There were 17 women (73.9%) and six men (26.1%) in the dementia care group, and 11 women (40.7%) and 16 men (59.3%) in the physical care group. The mean age of the caregivers was  $63.6 \pm 11.7$  years in the dementia care group and  $64.4 \pm 13.4$  years in the physical care group. The age of the participants was analyzed using the  $\chi^2$  test, and their gender was analyzed using the Mann-Whitney U test; no statistically significant difference was found between the two groups. The most common caregiver relationship was the daughter (13, 56.5%) in the dementia care group and the husband (seven, 25.9%) in the physical care group. The average duration of care was 73 months (minimum 12 months to a maximum of 480 months) in the dementia care group and 81 months (minimum three months to a maximum of 216 months) in the physical care group.

The gender of the care recipient was 17 women (73.9%) and six men

Table 1 Overview of the caregivers N = 50

	Dementia Care (n=23)	Physical Care (n=27)
Gender		
Women	17 (73.9%)	11 (40.7%)
Men	6 (26.1%)	16 (59.3%)
Mean age ± SD	63.6±11.7 years old	64.4±13.4 years old
Caregiver's relationship		
Daughter	13 (56.5%)	6 (22.2%)
Son	4 (17.4%)	6 (22.2%)
Daughter-in-law	2 (8.7%)	1 (3.7%)
Son-in-law	1 (4.3%)	2 (7.4%)
Wife	2 (8.7%)	3 (11.1%)
Husband	1 (4.3%)	7 (25.9%)
Sibling	0 (0.0%)	1 (3.7%)
Grandchild	0 (0.0%)	0 (0.0%)
Other	0 (0.0%)	1 (3.7%)
Average care period (Min. – Max.)	73 months (12 – 480 months)	81 months (3 – 216 months)

(26.1%) in the dementia care group and 21 women (77.8%) and six men (22.2%) in the physical care group. As for their ages, in the dementia care group, one (4.3%) was in their 60s or younger, two (8.7%) were in their 70s, 13 (56.5%) in their 80s, and seven (30.4%) were aged 90 years or older. In the physical care group, three (11.1%) were in their 60s or younger, 10 (37.0%) were in their 70s, seven (25.9%) in their 80s, and seven (25.9%) were aged 90 years or older.

## 2. The use of formal support

Formal support was used by seven (31.8%) regarding medical services, 13 (59.1%) regarding long-term care insurance services, and one (4.5%) regarding other services in the dementia care group. In the physical care group, six (25.0%) used medical services, 12 (50.0%) used the long-term care insurance service, and one (4.2%) used an independent support service. The percentage of respondents who did not use the service was five (22.7%) in the dementia care group and nine (37.5%) in the physical care group. As for whether the institutions and contact points could

Table 2 Comparison of the care burden N = 50

	J-ZBI_8	Dementia Care (n=23)	Physical Care (n=27)	p-Value
Total		6.0(4.0–14.0)	3.0(2.0–7.0)	0.028*
Personal strain		6.0(4.0–8.0)	3.0(1.0–6.0)	0.026*
Role strain		1.0(0.0–5.0)	1.0(0.0–2.0)	0.560

Notations are presented as medians (interquartile range).

\* p-value for Mann-Whitney U-test for differences between dementia care and physical care group.

\* Significance level was set at 0.05 (\*p<0.05)

be trusted and consulted regarding their care, 14 (60.9%) of the respondents in the dementia care group answered “yes,” six (26.1%) answered “no,” and three (13.0%) answered “no answer.” In the physical care group, 12 (44.4%) respondents answered “yes,” 12 (44.4%) answered “no,” and three (11.1%) answered “no answer.”

## 3. Comparison of the care burden (Table 2)

The median total score for all J-ZBI\_8 questions “total” was 6.0 (interquartile range: 4.0–14.0) and 3.0 (2.0–7.0) for the dementia and physical care groups, respectively. Personal strain scores were 6.0 (4.0–8.0) and 3.0 (1.0–6.0) for the dementia and physical care groups, respectively. Role strain scores were 1.0 (0.0–5.0) and 1.0 (0.0–2.0) for the dementia and physical care groups, respectively. The Mann-Whitney U test was conducted for the total score, personal strain score, and role strain score between the dementia and physical care groups. A statistically significant difference (p<0.05) was found between the two groups in the total score and personal strain score.

## 4. Status of informal support in the community (Table 3)

Regarding care cooperators, in the dementia care group, 11 (47.8%) of the respondents had someone who cooperated frequently, 11 (47.8%) had someone who cooperated occasionally, and one (4.3%) had no one. In the physical care group, 11 (40.7%) of the respondents said they had

Table 3 Status of informal support in the community N = 50

	Dementia Care (n=23)		Physical Care (n=27)	
Availability of the care cooperators				
They cooperate frequently	11	(47.8%)	11	(40.7%)
They cooperate sometimes	11	(47.8%)	10	(37.0%)
No one cooperates	1	(4.3%)	6	(22.2%)
Availability of community members who supported them				
Exist	9	(39.1%)	6	(22.2%)
Do not exist	10	(43.5%)	18	(66.7%)
No answer	4	(17.4%)	3	(11.1%)
Necessity of connecting with community members and helping each other				
Necessary	15	(65.2%)	13	(48.1%)
Somewhat necessary	7	(30.4%)	11	(40.7%)
Not very necessary	0	(0.0%)	2	(7.4%)
Not necessary	0	(0.0%)	1	(3.7%)
No answer	1	(4.3%)	0	(0.0%)
Whether or not help from community members was actually required				
Required	5	(21.7%)	6	(22.2%)
Not required	18	(78.3%)	21	(77.8%)

someone who cooperated frequently, 10 (37.0%) had someone who cooperated occasionally, and six (22.2%) had no one. Multiple answers were given for the relationship of the caregivers. Therefore, the denominator of the ratio was the number of respondents in each group. There were 22 respondents for dementia care and 21 respondents for physical care. (Figure 1.) In the dementia care group, there were nine (40.9%) spouses, six (27.3%) children, and five (22.7%) siblings. In the physical care group, there were 12 (57.1%) siblings, nine (42.9%) children, and six (28.6%) spouses.

Regarding the availability of community members who supported them in the dementia care group, nine (39.1%) respondents answered "yes," 10 (43.5%) answered "no," and four (17.4%) answered "no answer." In the physical care group, six (22.2%) respondents answered "yes," 18 (66.7%) answered "no," and three (11.1%) answered "no answer."

Regarding the necessity of connecting with community members and helping each other, 15 (65.2%) of the respondents in the dementia care group required it,

seven (30.4%) somewhat required it, zero (0.0%) did not require it as much, zero (0.0%) did not require it, and one (4.3%) did not answer. In the physical care group, 13 (48.1%) required it, 11 (40.7%) somewhat required it, two (7.4%) did not require it as much, one (3.7%) did not require it, and zero (0.0%) did not answer.

Regarding whether or not they actually wanted community members to help them, in the dementia care group, five (21.7%) respondents answered "yes" and 18 (78.3%) answered "no." In the physical care group, six (22.2%) respondents answered "yes" and 21 (77.8%) answered "no."

Caregivers were asked to select five things they particularly wanted the community members to help them with a list of 14 alternatives. As there were multiple responses, the denominator for the ratio was the number of respondents in each group. The number of respondents for dementia care and for physical care was nine each. (Figure 2) In the dementia care group, four (44.4%) respondents wanted them to be involved in "watching over," three (33.3%) in "talking to the care recipient," and three (33.3%) in "managing outside the house: taking out the trash, weeding, etc." In the physical care group, five (55.6%) respondents wanted "transportation by car," three (33.3%) wanted "watching over," and three (33.3%) wanted help with "general housework."

## Discussion

Based on the results of this study, we outlined the need for informal support required by the different types of caregivers (dementia care and physical care) and examined each of their characteristics.

### 1. Level of care burden

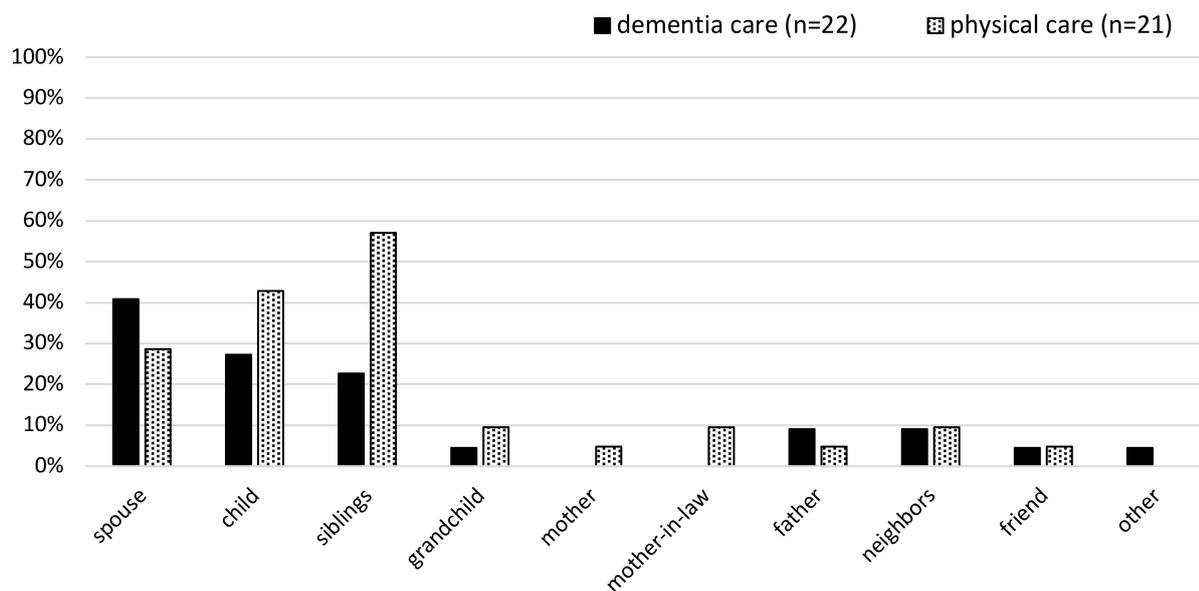


Fig.1 Relationship of the care cooperator

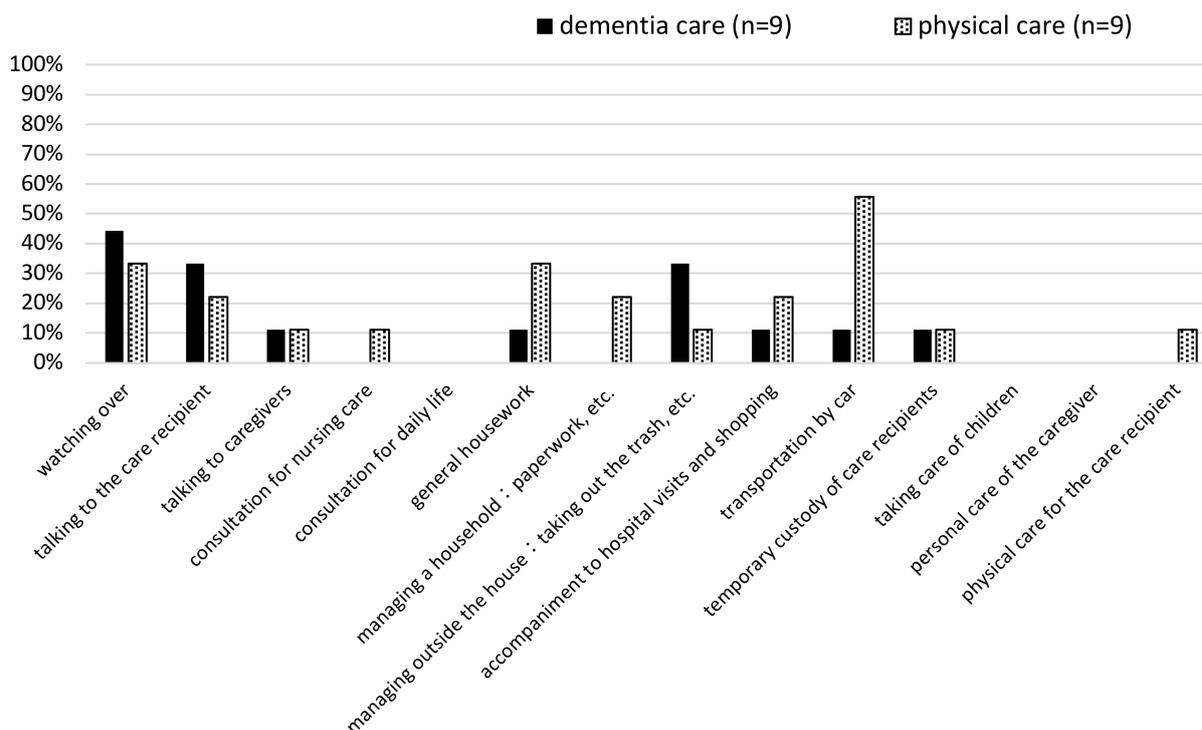


Fig.2 Reasons for which caregivers particularly wanted community members' help

In this study, the level of care burden was measured using the J-ZBI\_8. In previous studies, the cutoff value for the total score was 13 points, and a score of 13 or higher is said to be a high-risk group for care burden (14). The median scores for both groups were well below 13

points, which indicated that the burden of care was low for the participants in this study. This may be because the degree of care required by the care recipients of the participants in this study was not very high. However, the cause of this phenomenon is unclear

because the level of care required by the care recipients was not investigated in this survey. This is an issue for the future. Both groups had a mild level of care burden, but when the total score of J-ZBI\_8 between the two groups was compared, the care burden was significantly higher in dementia care than in physical care. This result was consistent with the findings of previous studies (10).

In addition, dementia care was significantly higher than physical care regarding personal strain (negative feelings toward the situation that necessitated care), a factor in the J-ZBI\_8. Therefore, it can be assumed that personal strain played a major role in the difference in care burden between dementia care and physical care. Previous studies (15) have shown that a care recipient's poor memory and problem-solving skills are related to factors that increase personal strain in family caregivers of people with dementia. This decline in ability is thought to be due to the blurring of the boundary between age-related and pathological changes, which makes it easy for caregivers to view care negatively due to their lack of knowledge regarding dementia and their reluctance to accept it. Therefore, negative feelings regarding the care situation are more likely to increase during dementia care than during physical care.

## **2. Status of informal caregiver cooperators**

In this study, the majority of the care cooperation was provided by relatives, such as family members (spouses and siblings) in both groups. Family caregivers in rural Japan reported that emotional support within the family was effective in reducing the burden of caregiving (16). In this study, a

factor that contributed to the low level of burden of care among the participants was enhanced cooperation by their families. Conversely, the number of cooperators other than relatives, such as neighbors and friends, was small, which was the same trend as in previous studies (5). To continue care in a familiar community, it is important that care be supported cooperatively by the entire community (7).

In this study, dementia caregivers had a higher percentage of community members willing to support their care than physical caregivers. However, the burden of care was higher in dementia care than in physical care, even though there were community members who supported them. This suggested the need to review the support that dementia caregivers receive from community members. In addition, a high percentage of respondents did not have community members who supported them in physical care. This could be because the burden of care was still low and, therefore, did not require support. However, as the level of care of the care recipient is expected to increase in the future, connecting them to the local residents who are supportive at an early stage may allow them to continue their care without increasing the burden of care in the future.

## **3. The need for informal support by community members**

In this section, we consider the specific support provided by the community members. Approximately 90% of the caregivers in both groups responded that it was "necessary" or "somewhat necessary" for them to connect with and help each other in the community. However, approximately 80% of the respondents in both groups said that they did not require help from community members. The background to

these contradictory answers may be as follows. First, when the care recipient's care needs are mild and they do not need support from community members. However, in this survey, we were not able to confirm the level of care required by the care recipient. Hence, further investigation is required into the same. Previous studies (9,17) reported that people with dementia and their families did not actively seek informal support from community members. It has also been reported that the reason behind non-help seeking was the desire to "not burden human relations, so just a greeting is fine" (9) or "to not want people to think that their family is cutting corners" (17). For caregivers who feel this way, it is likely they will find it more difficult to ask for help from community members on their own.

Therefore, it is necessary to adopt a proactive and concrete approach to seek the support of community members.

Regarding specific support that the caregivers sought from community members, we found that dementia caregivers required support for their care recipient in the form of "watching over" and "talking to the care recipient." This result supported the results of previous research, which showed that informal support requires "psychosocial care," such as emotional support, hobby activities, and interpersonal interaction (4). In particular, in dementia care, caregivers must always be careful to prevent the person with dementia from falling ill or having accidents. However, it is often difficult for them to do this alone (18). Therefore, they sought support such as "watching over" and "talking to the care recipient." Caregivers are unlikely to be able to go out of the house to dispose the trash or weeds, among others, while watching over the care recipient.

Regarding physical care, the most frequently sought support was "transportation by car." This could be due to the difficulty in moving due to the reduced mobility of the care recipient. A prior study (4) has reported that physical care is sought through formal support. In this study, informal support was requested for car transportation, which suggested that formal support for going out was insufficient. In addition, the percentage of "general housework" was high in the physical care category. This may be related to the large percentage of male caregivers. In the case of men who have never done housework before, they may find it difficult to maintain their daily lives and care for themselves while caring for another individual.

In addition, a common feature of the support sought by the family caregivers for dementia care and physical care during this time could be because supporting the care recipient, rather than directly supporting the family caregivers themselves, may lead to physical and mental respite for the family caregivers. This phenomenon shows the importance of considering not only the situation of the care recipient but also the impact on the family caregiver's quality of life when assessing the need for support (3).

As described above, caregivers sought support in many areas that community members could easily provide, such as "watching over," "talking to the care recipient," "transportation by car," "managing outside the house: taking out the trash, weeding, etc." and "general housework." However, it may be difficult for caregivers to request support from community members due to reticence or shame. Therefore, it is necessary for community members to understand the specifics of caregivers' support to create a system where community members can

actively communicate the support they can provide.

### **Research limitations**

This study has a limitation. As this study was conducted in one town, it is difficult to generalize the results. This study used a part of a larger survey of all households, including residents who were not caregivers, and thus lacked information on the status of the caregivers and details of their care.

In the future, it will be necessary to narrow the target to only caregivers and examine the differences in the informal support sought by the different types of care, focusing on different types of dementia and physical disabilities as well as the different levels of care required. It is also important to consider the caregivers' feelings regarding receiving informal support from the local residents.

### **Conclusion**

Based on the total and personal strain scores of the J-ZBI\_8, the care burden was significantly higher in dementia care than in physical care.

Informal support by community members is necessary as most of the caregiver cooperators in both dementia and physical care groups were family members, and there were few non-family members who could help.

In both groups, approximately 90% of the respondents required connections and help from community members. However, approximately 80% of the respondents also said that they did not actually require help. This may have been related to caregivers' reticence and shame toward seeking help from community members.

The most common type of support requested from community members

were "watching over" and "talking to the care recipient" for dementia care, and "transportation by car" for physical care.

It is necessary to create a system where community members are made aware of the specific support that caregivers seek and actively communicate what they can do to help.

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### **Conflicts of interest**

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There are no conflicts of interests to declare.

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# 介護の種類の違いによる家族介護者が求めるインフォーマルな支援の 特性 ～認知症介護と身体介護の比較から～

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## 要旨

本研究は、在宅において認知症介護または身体介護をしている家族介護者におけるインフォーマルな支援の必要性を概観し、介護の種類の違いによる家族介護者が求めるインフォーマルな支援の特性を検討することを目的とした。

対象者は、北日本の農村地域である A 町の全世帯を対象として実施されたアンケート調査結果より抽出した、認知症をもつ者の介護者（認知症介護）23 名と身体障がいをもつ者の介護者（身体介護）27 名の計 50 名とした。調査内容は、介護負担度、介護協力者の状況、地域住民との助け合いの状況、地域住民に求める支援であった。

介護負担度は全体的に軽度であったが、認知症介護が身体介護よりも有意に高かった。介護協力者は両介護とも家族による協力が多く、地域住民による支援は少なかった。両介護者とも約 9 割が地域住民とのつながりや助け合いは必要であるが、約 8 割が手伝ってほしいことはないと回答した。また、地域住民に求める具体的な支援内容は、認知症介護では「見守り」と「被介護者の話し相手」、身体介護では「車での送迎」であった。

介護者は地域住民からのインフォーマルな支援に対する遠慮や羞恥心があることが推測された。本研究で明らかになった認知症介護と身体介護それぞれの介護者が求める具体的な支援内容について、地域住民側から介護者に対して積極的に発信してく仕組み作りが必要である。

キーワード：インフォーマルな支援、家族介護者、認知症介護、身体介護