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## **The Decision-Making and Communication Capacities of Older Adults with Dementia: A Population-Based Study**

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*The Open Nursing Journal, Volume 8, 2014*

**ISSN:** 1874-4346/14

**DOI:** 10.2174/1874434620140512001

**Article Type:**

**Received:** January 19, 2014

**Revised:** April 29, 2014

**Accepted:** May 02, 2014

**Provisional PDF Publication Date:** May 12, 2014

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**Research Article**

**Title:** The decision-making and communication capacities of older adults with dementia: A population-based study

**Running title:** Decision-making and communication capacities of older adults with dementia

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**Conflict of Interest :**

Kazuko Mitoku, PhD, RN has received the research grant from JSPS KAKENHI Grant Number (15592348, 20592645), but has no conflict of interest to disclose.

Setsu Shimanouchi, PhD, RN has no conflict of interest to disclose.

**Acknowledgements:**

We thank Dr. Yoshiyuki Sakamoto of the Medical Association in Gujo City; Dr. Masumi Minowa, the former department director of National Institute of Public Health; the late Dr. Toshiharu Fujita of the Institute of Statistical Mathematics; and Ms. Tomoko Kawaguchi.

## **Abstract**

The present study assessed the decision-making and communication capacities of older adults with dementia who required assistance and care and measured the subsequent changes in these capacities. Of 845 older adults who received long-term care between April 2003 and December 2004, about half of them without dementia were excluded and the remaining 448 were finally included in the analyses. These individuals were completed follow-up for assessment for two years. The data were obtained from the Long-Term Care Insurance Certification Committee for Eligibility in Gujo City. A total of 73.7% of people with dementia were somewhat capable of making decisions (32.4% were reported as being “always capable”; 41.3% were reported as being “sometimes capable”). A total of 93.7% were somewhat capable of communicating with others (78.3% were reported as being “always capable”; 15.4% were reported as being “sometimes capable”). The results indicate that older adults with dementia can participate in their own care decisions, even if they require assistance and support in their daily lives. The present study shows, however, that baseline decision-making capacity declined to about half what they were after one year and to about one-third of what they were after two years, suggesting that earlier efforts are needed to ensure that the preferences of individuals with dementia are reflected in their care.

**Keywords:** older adults, dementia, decision-making, communication capacity, follow up, change

## **Introduction**

There is a global focus on dementia. Currently, 44 million people worldwide are affected by dementia, and this number is expected to triple (135 million) by 2050 due to the aging world's population [1].

Urgent action is needed, particularly in rapidly aging countries. Japan has the highest life expectancy in the world (85.90 years for women and 79.44 years for men) [2], with one in four residents being 65 and over. A long-term care insurance program was launched in 2000 to provide necessary services to help older adults perform routine daily activities while maintaining dignity and autonomy. Dementia needs special attention, since at least 15.3% of the recipients of long-term care insurance requires assistance and care in daily living due to dementia [3].

Older adults wish to live out their last days according to their own decisions, even though they need assistance and care. Treating older adults with dignity is a challenge for both their families and society in general. Older adults should be supported in making their own decisions by ensuring that their wishes are respected and by maintaining open communication with them. Persons with dementia, however, are often assumed to be difficult to communicate with [4], because the disease impairs communication abilities as it progresses over time [5]. Not only short-term memory and recognition problems but also behavioral and psychological symptoms of dementia (BPSD) may create communication barriers. BPSD is a group

of non-cognitive symptoms, including delusions, hallucinations, aggression, agitation, and wandering, which are commonly observed in persons with dementia [6, 7, 8]. These symptoms hinder providing care based on the needs and preferences of the persons with dementia. However, people with severe dementia exhibit episodes of lucidity that are often associated with closer contact with care providers [9], and they may be able to retain their decision-making capacities [4, 5].

The issue of impaired decision-making affects the lives of people with dementia. Family caregivers face considerable difficulties in making decisions about placing their loved ones in a care facility, and the wishes of the person with dementia are not often taken into consideration [10]. Some long-term care decisions can prove to be particularly controversial, including tube feeding and gastrostomies in dementia [11]. Such decisions should be made based on the preferences of the patient, but sometimes the preferences are difficult to ascertain, and tube feeding often continues even after all other forms of life support are stopped [12].

Despite these problems with decision making and maintaining communication with people with dementia, previous studies have mainly focused on interviews with family caregivers due to the impaired cognitive abilities of the individuals with dementia. Although health care providers are aware of the importance of

letting the individuals with dementia make decisions themselves, there are few population-based studies that include interviews with people with dementia and that even make an attempt to assess their decision-making and communication capacities. Since decision-making capacity in people with dementia is not fully understood, objective and epidemiological studies are needed for dementia policy planning.

The objectives of the present study were to assess the decision-making and communication capacities of people with dementia who required assistance and care and to identify subsequent changes in their capabilities.

## **Materials and Methodology**

### **1. Subjects and Setting**

This study was conducted in Gujo City, Gifu Prefecture of Japan, with a population of 49,286 in April 2003; ; 28.6% of them (n= 14100) were people aged 65 or above. Of these older people, 845 community-dwelling older adults were certified as new recipients of the long-term care insurance program in Gujo City between April 2003 and December 2004. While about half of them without

dementia were excluded, 448 of these care recipients were included in this study and were followed up for two years.

This study was conducted in Gujo City, Gifu Prefecture, Japan (baseline population in April 2003: 49,286; proportion of people aged 65 and over: 28.6%). The subjects of the present study were 845 community-dwelling older adults aged 65 and over who were certified as new recipients of the long-term care insurance program in Gujo City between April 2003 and December 2004. Of the 845, 448 older adults with dementia were included in the analyses, and we followed up with these older adults with dementia for two years.

## **2. Data Collection**

We used the secondary data obtained from the Long-Term Care Insurance Certification Committee for Eligibility in Gujo City, together with the mortality data directly obtained from municipal residence registry. In Japan, trained investigators conduct on-site assessment of applicants' mental and physical

conditions by using a standardized 79-item national questionnaire when the application is made by the individual or his/her family to make use of services in the public long-term care insurance system services. For initial assessment, the applicant is either classified into one of three levels of dependency and five levels of cognitive function or is rejected outright by the computer. For the second assessment, a local independent committee consisting of five professionals in medicine, health care and welfare, reviews the computer result with a physician's report. Then, the certification committee determines eligibility and levels of needs. We used the results of the second assessment as the data of the present study. After their initial application for the insurance program, the recipients would apply for a renewal every six months, or for changes whenever their living and/or health conditions changed. These investigation data at renewal or condition change were used as the follow-up data.

In the present study, levels of dependency and dementia as assessed by the local certification committee were used (Table 1). There are three levels of dependency (independent, pre-bedridden, bedridden). The questionnaire assesses the activities of daily living (ADLs) of each person, including transference, movement, feeding, bladder and bowel control, oral hygiene, face-washing, grooming, dressing and swallowing functions. Dementia is measured in this study by its presence "yes (present)" or absence "no (absent)" and it is further described by examining the following characteristics: (1) cognitive function (remembering how to complete daily activities, recognizing their own dates of birth, short-term memory,



and recognizing/knowing their own name, the current season, and their current setting); and (2) BPSD (e.g., resistance to care, hallucinations, unstable emotions, wandering, agitation, feelings of persecution, and confabulation ability). There are five levels of dementia: I – IV and M (mental symptoms). In the present study, we classified I and II as “mild,” III as “moderate,” and IV and M as “severe.”

Table 1. Levels of Dependency and Dementia, and Decision-Making and Communication Capacities [19].

Item	Capacity Level	Criteria	
Level of Dependency	Independent	Mostly independent for feeding, bladder/bowel, and dressing.	
	Pre-bedridden	Partially dependent for feeding, bladder/bowel, and dressing.	
	Bedridden	Totally dependent for feeding, bladder/bowel, and dressing. Severe dementia is included.	
Level of Dementia	Mild (I-II)	Mostly independent with assistance despite cognitive impairment, symptoms/behavior or communication difficulty with assistance.	
	Moderate (III)	Requires care due to symptoms/behaviors or communication difficulties.	
	Severe (IV-M)	Totally dependent due to frequent symptoms/behaviors or communication difficulty. Requires specialty mental care due to severe mental or physical health problems.	
Decision Making Capacity	Always Capable	Always Capable	Always capable of making decisions in any circumstance.
	Sometimes Capable	Sometimes Capable	Capable of making decisions in familiar situations, but assistance is required for participation in treatment and care planning.
	Incapable	Mostly incapable, extreme difficulties	Very difficult to make decisions in daily living with some exceptions (e.g., able to choose TV programs, meals, or clothing).
		Incapable	Incapable of making any decisions.
Communication Capacity	Always Capable	Always Capable	Always capable of communicating with anyone.
	Sometimes Capable	Sometimes Capable	Usually capable of communicating with family/caregiver. Difficulty depends on contents.
	Incapable	Mostly incapable	Incapable of communicating with family/caregiver except for limited messages (e.g., “painful,” “hungry”) that can be occasionally conveyed to a specific person.
		Incapable	Incapable of communicating with anyone.

The investigator interviewed the individuals with dementia to assess whether they had sufficient capacity to make decisions on their own and whether they had the ability to communicate with others.

Decision-making capacity was assessed by four levels: “always capable,” “sometimes capable,” “mostly difficult,” and “incapable.” For analysis, “mostly difficult” and “incapable” were combined into one value, “incapable.” Communication was assessed not by responses to a question but by whether the individual was capable of conveying his/her desire to others in daily activities by categorizing the behavior into one of four levels: “always capable,” “sometimes capable,” “mostly incapable,” and “incapable.” For analysis, “mostly incapable” and “incapable” were combined into one value, “incapable.” Communication, as described in this study, was not limited to conversation. It also included writing and expressive gestures. For example, when the participants with aphasia communicated with the investigator using their gestures, the investigator would place a check mark in either “always capable” or “sometimes capable.”

### **3. Analysis**

We performed a Mann-Whitney U test and a Kruskal-Wallis test to examine the association between decision-making and communication capacities and their related factors (sex, age group, level of dependency, level of dementia, cognitive function and BPSD). An one-way ANOVA test was used to calculate the mean of six items of cognitive function and 18 BPSD items (“present” was calculated as one point), and the Welch’s method was used to examine the differences of means. The Pearson’s correlation coefficient was used to assess the associations between the older people’s decision-making and their

communication capacities. The PASW Statistics 18.0 for Windows was used for all of the above statistical analyses; p values less than 0.05 were considered significant.

#### **4. Ethical Considerations**

This study complied with the Ethical Guidelines of Epidemiological Research (Ministries of Education, Culture, Sports, Science and Technology, and Health, Labour and Welfare) and the Guidelines of Good Epidemiological Practice. This study was approved by the institutional review boards of the National Institute of Public Health (No. NIPH-IBR 03006). All participants provided verbal and written informed consent with the use of the program and clinical record data would be used for research purposes only, when they were certified as the recipients of the long-term care insurance program.

#### **Results**

##### **1. Prevalence of dementia and level of dependency**

In 845 older adults who required assistance and care, 68 (43.0%) of 158 people aged 65 and 74 years, 204 (51.0%) of 400 people aged 75 and 84 years, and 176 (61.3%) of 287 people aged 85 and over were suffering from dementia. The proportion of dementia increased as the individuals aged ( $p < 0.001$ ).

## 2. Decision-making capacity and associated factors (Table 2)

### 1) Decision-making capacity

Of the 448 persons with dementia, 145 (32.4%) were always capable of making decisions and 185 (41.3%) were sometimes capable of making decisions, while 118 (26.3%) were incapable. Forty (23.7%) men were always capable of making decisions and 75 (44.4%) were sometimes capable of making decisions, while 54 (32.0%) were incapable. Among women, 105 (37.6%) were always capable of making decisions and 110 (39.4%) were sometimes capable of making decisions, while 64 (22.9%) were incapable. Men were significantly more likely to be incapable to decisions than women ( $p = 0.001$ ).

### 2) Decision-making capacity by level of dependency

One hundred seventy persons with dementia were independent (37.9%). As more persons became bedridden, the number of persons deemed to have adequate decisional capacity decreased ( $p < 0.001$ ).

### 3) Decision-making capacity by level of dementia

In persons with mild dementia, 142 persons (39.0%) were always capable of making decisions, and 169 (46.4%) were sometimes capable of making decisions. By combining “always capable” and “sometimes

capable,” a total of 85.4% of persons with dementia with mild was somewhat capable of making decisions, however, this number decreased as the dementia progressed (32.1% in moderate dementia; 0% in severe dementia;  $p < 0.001$ ). As persons with dementia aged, more persons had a greater decisional capacity: 17 persons (25.0%) aged 65 – 74 years; 65 (31.9%) aged 75 - 84; 60 (38.7%) in 85 years and over ( $p = 0.003$ ).

#### 4) Mean cognitive function score and decision-making capacity

Mean cognitive function scores were 1.98 (SD 2.03) in the 65 – 74 age category, 1.25 (SD 0.65) in the 75 – 84 age category, and 1.19 (SD 1.67) in the 85 years and over age category. Younger adults had higher mean cognitive function score than older adults ( $p = 0.039$ ). When mean cognitive function scores were compared among the age groups by decision-making capacity, there were no significant differences among persons with “always capable,” “sometimes capable,” and “incapable” categories of making decisions.

Table 2. Sex, Age Group, Levels of Dependency and Dementia, and Decision-Making Capacity.

		Decision Making Capacity (%)					
		Always	Sometimes	Incapable	Total	p	
	Total	145 (32.4)	185 (41.3)	118 (26.3)	448		
Sex	Male	40 (23.7)	75 (44.4)	54 (32.0)	169		
	Female	105 (37.6)	110 (39.4)	64 (22.9)	279	0.001 i)	
Level of Dependency	Independent	65 (38.2)	72 (42.4)	33 (19.4)	170		
	Pre-bedridden	61 (35.5)	73 (42.4)	38 (22.1)	172	<0.001 ii)	
	Bedridden	19 (17.9)	40 (37.7)	47 (44.3)	106		
Level of Dementia	Total	Mild (I - II)	142 (39.0)	169 (46.4)	53 (14.6)	364	
		Moderate (III)	3 (5.1)	16 (27.1)	40 (67.8)	59	<0.001 ii)
		Severe (IV - M)	0 (0.0)	0 (0.0)	25 (100.0)	25	
	Mild (I – II)	65-74 (yrs)	17 (25.0)	22 (45.8)	9 (18.8)	48	
		75-84	65 (31.9)	72 (44.7)	24 (14.9)	161	0.731 ii)
		85 and over	60 (38.7)	75 (48.4)	20 (12.9)	155	
Moderate (III)	65 - 74 (yrs)	0 (0.0)	4 (33.3)	8 (66.7)	12	**	
	75 - 84	1 (0.5)	8 (25.0)	23 (71.9)	32	0.619 ii)	
	85 and over	2 (13.3)	4 (26.7)	9 (60.0)	15		
Severe (IV – M)	65-74 (yrs)	0 (0.0)	0 (0.0)	8 (100.0)	8		
	75-84	0 (0.0)	0 (0.0)	11 (100.0)	11	—	

	85 and over	0 (0.0)	0 (0.0)	6 (100.0)	6		
Mean Cognitive	65-74 (yrs.)	0.12 (SD 0.33)	1.84(SD 1.80)	3.40 (SD 1.84)	1.98(SD 2.03)	<0.001	iii)
Function Score	75-84	0.27 ( 0.69)	0.92( 1.36)	2.82 ( 1.65)	1.25( 1.65)	<0.001	iii)
(SD)	85 and over	0.37 ( 0.91)	0.86( 1.21)	3.40 ( 1.71)	1.19( 1.67)	<0.001	iii)
Difference of Mean	p iii)	0.457	0.041	0.198	—	—	
Score by Age Group							

- i) Mann-Whitney U test
- ii) Kruskal-Wallis test
- iii) Welch's method



### 3. Correlation between communication and decision-making capacities (Table 3)

Of the 448 persons with dementia, 351 (78.3%) were always capable of communicating, 69 (15.4%) were sometimes capable of communicating, and only 28 (6.3%) were incapable of communicating with others.

By combining “always capable” and “sometimes capable,” a majority of people with dementia were classified as somewhat capable to communicate with others. Of those who had communication capacity, 40.5% were always capable of making decisions, 45.3% were sometimes capable of making decisions, and 14.2% were incapable. As communication capacity declined, so did decision-making ability ( $r = 0.499, p < 0.001$ ).

Table 3. Relation between Decision-Making and Communication Capacities.

		Communication Capacity (%)				Correlation Coefficient		U test,	
		Always	Sometimes	Incapable	Total	Pearson's r	p	p	
Decision-Making Capacity	Total	351 (100)	69 (100)	28 (100)	448	—	—	—	
	Total	Always Capable	142 (40.5)	3 (4.3)	0 (0.0)	145	0.499	<0.001	—
		Sometimes Capable	159 (45.3)	23 (33.3)	3 (10.7)	185			
		Incapable	50 (14.2)	43 (62.3)	25 (89.3)	118			
		Total	142 (97.9)	3 (2.1)	0 (0.0)	145			
	Always Capable	65-74 (yrs)	17 (100.0)	0 (0.0)	0 (0.0)	17	0.561	<0.001	—
		75-84	64 (97.0)	2 (3.0)	0 (0.0)	66			
		85 and over	61 (98.4)	1 (1.6)	0 (0.0)	62			
		Total	159 (85.9)	23 (12.4)	3 (1.6)	185			
	Sometimes Capable	65-74 (yrs)	18 (69.2)	6 (23.1)	2 (7.7)	26	0.408	<0.001	0.024
		75-84	71 (88.8)	8 (10.0)	1 (1.3)	80			
		85 and over	70 (88.6)	9 (11.4)	0 (0.0)	79			
Total		50 (42.4)	43 (36.4)	25 (21.2)	118				
Incapable	65-74 (yrs)	6 (24.0)	14 (56.0)	5 (20.0)	25	0.570	<0.001	0.014	
	75-84	33 (56.9)	16 (27.6)	9 (15.5)	58				
	85 and over	11 (31.4)	13 (37.1)	11 (31.4)	35				
	Total	50 (42.4)	43 (36.4)	25 (21.2)	118				

#### 4. BPSD and decision-making capacity (Table 4)

Regarding BPSD, 357 persons with dementia (79.8%) had at least one of 19 symptoms. Among those with decisional capacity, 102 (70.3%) in the “always capable” category and 155 (83.7%) in the “sometimes capable” category had BPSD. Among those without decisional capacity, 100 (84.7%) had BPSD. As they lost decision-making capacity, BPSD prevalence grew ( $p = 0.002$ ).

Mean BPSD increased, as decision-making capacity declined: 1.94 (SD 2.24) for “always capable”; 2.35 (SD 2.18) for “sometimes capable”; and 4.26 (SD 3.66) for “incapable.” Although persons without decisional capacity in the 85 years and over age category had more symptoms ( $p = 0.032$ ), there were no significant differences between decision-making capacity and BPSD in the 65-74 years and the 75-84 years categories ( $p = 0.175$ ,  $p = 0.122$ , respectively). More people with BPSD than those who were not classified as having BPSD were incapable of making decisions.

Table 4. BPSD and Decision-Making Capacity

		Decision Making Capacity (%)				p <sup>a</sup>		
		Always	Sometimes	Incapable	Total			
計		145 (32.4)	185 (41.3)	118 (26.3)	448			
BPSD Total (ANOVA)	Mean	1.94	2.35	4.26	2.59	<0.001 <sup>b</sup>		
	SD	2.24	2.18	3.66	2.69			
Age Group (yrs)	BPSD	Absent	43 (47.3)	30 (33.0)	18 (19.8)	91	0.002	
		Present	102 (28.6)	155 (43.4)	100 (28.0)	357		
	65-74	Absent	5 (41.7)	4 (33.3)	3 (25.0)	12	0.175	
		Present	12 (21.4)	22 (39.3)	22 (39.3)	56		
	75-84	Absent	17 (45.9)	11 (29.7)	9 (24.3)	37	0.122	
		Present	49 (29.3)	69 (41.3)	49 (29.3)	167		
	85 and over	Absent	21 (50.0)	15 (35.7)	6 (14.3)	42	0.032	
		Present	41 (30.6)	64 (47.8)	29 (21.6)	134		
	BPSD	Repetitive sentences	Present	35 (26.3)	57 (42.9)	41 (30.8)	133	0.057
		Day-night reversal	Present	27 (23.7)	45 (39.5)	42 (36.8)	114	0.002
Resistance to care		Present	14 (14.9)	33 (35.1)	47 (50.0)	94	<0.001	
Illusions and delusions		Present	14 (20.3)	26 (37.7)	29 (42.0)	69	0.001	
Emotional instability		Present	20 (29.9)	18 (26.9)	29 (43.3)	67	0.029	
Carelessness with fire		Present	23 (36.5)	26 (41.3)	14 (22.2)	63	0.356	
Feelings of persecution		Present	17 (27.4)	25 (40.3)	20 (32.3)	62	0.230	
Wandering		Present	9 (14.8)	23 (37.7)	29 (47.5)	61	<0.001	

Aggression	Present	8 (13.1)	20 (32.8)	33 (54.1)	61	<0.001
Wanting to go out alone	Present	8 (14.0)	16 (28.1)	33 (57.9)	57	<0.001
Confabulation	Present	14 (26.9)	22 (42.3)	16 (30.8)	52	0.320
Screaming	Present	6 (12.2)	15 (30.6)	28 (57.1)	49	<0.001
Restlessness	Present	6 (13.0)	17 (37.0)	23 (50.0)	46	<0.001
Not able to go home	Present	7 (17.5)	17 (42.5)	16 (40.0)	40	0.013
Hoarding	Present	4 (21.1)	6 (31.6)	9 (47.4)	19	0.063
Breaking objects and clothes	Present	2 (14.3)	3 (21.4)	9 (64.3)	14	0.006
Dirty conduct	Present	3 (37.5)	4 (50.0)	1 (12.5)	8	0.488
Eating inedible objects	Present	0 (0.0)	2 (25.0)	6 (75.0)	8	0.002

<sup>a</sup> Mann-Whitney U test was used unless it was specified.

<sup>b</sup> Welch's method was used.

## 5. Decision-making capacity by age group and change at two years (Table 5)

The number of persons with decisional capacity decreased at one year (83, 57.2%) and two years (44, 30.3%) from baseline. Of 185 persons who were sometimes capable of making decisions at baseline, 16 (8.6%) and 11 (5.9%) improved to fit the “always capable of making decisions” category at one year and two years, respectively. Of 118 persons who were incapable of making decisions at baseline, 15 (12.5%) and 13 (11.0%) improved to fit “somewhat capable of making decisions” category at one year and two years, respectively.

At one year follow-up, the number of persons with dementia with decisional capacity decreased to almost half what it was at the baseline, including 9 (52.9%) in the 65-74 years category, 38 (57.6%) in the 75-84 years category, and 36 (58.1%) in the 85 years and over category. There were no significant differences among age groups ( $p = 0.782$ ). Similarly, the number of persons with dementia who maintained decisional capacity decreased to about one-third the baseline level at two years: 6 (35.3%) in the 65-74 years category, 22 (25.8%) in the 75-84 years category, and 16 (25.8%) in the 85 years and over category. There were no significant differences between the age groups ( $p = 0.309$ ).

Similar improvement was observed at two years. Of the persons who were sometimes capable of making decisions at baseline, 2 (7.7%) in the 65 -74 years category, 10 (12.5%) in the 75-84 years category, and 4 (5.1%) in the 85 years and over category had improved to always capable. Of the persons who were incapable of making decisions at baseline, 5 (20.0%) in the 65 -74 years category, 7 (12.0%) in the 75-84 years category, and 4 (11.4%) in the 85 years and over category had improved to somewhat capable.

Although the number of people with decisional capacity decreased to about half at one year and about one-third at two years follow-up, there were no significant differences between their age groups. Some persons improved their decision-making capacity over time.

Table 5. Change of Decision-Making Capacity by Level of Dementia and Age Group over 2 years

Age (yrs)		Change of Decision Making capacity (%)										
		1 year						2 years				
		Total	Always	Sometimes	Incapable	Unknown	Death	Always	Sometimes	Incapable	Unknown	Death
Total	Total	448	102 (22.8)	138 (30.8)	103 (23.0)	19 (4.2)	86 (19.2)	57 (12.7)	114 (25.4)	98 (21.9)	55 (12.3)	124 (27.7)
	Always	145	83 (57.2)	24 (16.6)	9 (6.2)	6 (4.1)	23 (15.9)	44 (30.3)	38 (26.2)	12 (8.3)	19 (13.1)	32 (22.1)
	Sometimes	185	16 (8.6)	101 (54.6)	27 (14.6)	10 (5.4)	31 (16.8)	11 (5.9)	65 (35.1)	32 (17.3)	24 (13.0)	53 (28.6)
	Incapable	118	3 (2.5)	13 (11.0)	67 (56.8)	3 (2.5)	32 (27.1)	2 (1.7)	11 (9.3)	54 (45.8)	12 (10.2)	39 (33.1)
65-74	Total	68	13 (19.1)	19 (27.9)	19 (27.9)	12 (17.6)	5 (7.4)	10 (14.7)	16 (23.5)	17 (25.0)	12 (17.6)	13 (19.1)
	Always	17	9 (52.9)	3 (17.6)	0 (0.0)	4 (23.5)	1 (5.9)	6 (35.3)	6 (35.3)	0 (0.0)	2 (11.8)	3 (17.6)
	Sometimes	26	2 (7.7)	13 (50.0)	5 (19.2)	6 (23.1)	0 (0.0)	2 (7.7)	7 (26.9)	4 (15.4)	7 (26.9)	6 (23.1)
	Incapable	25	2 (8.0)	3 (12.0)	14 (56.0)	2 (8.0)	4 (16.0)	2 (8.0)	3 (12.0)	13 (52.0)	3 (12.0)	4 (16.0)
75-84	Total	204	49 (24.0)	61 (29.9)	53 (26.0)	7 (3.4)	34 (16.7)	28 (13.7)	46 (22.5)	51 (25.0)	28 (13.7)	51 (25.0)
	Always	66	38 (57.6)	11 (16.7)	4 (6.1)	2 (3.0)	11 (16.7)	22 (33.3)	17 (25.8)	6 (9.1)	8 (12.1)	13 (19.7)
	Sometimes	80	10 (12.5)	44 (55.0)	12 (15.0)	4 (5.0)	10 (12.5)	6 (7.5)	25 (31.3)	15 (18.8)	12 (15.0)	22 (27.5)
	Incapable	58	1 (1.7)	6 (10.3)	37 (63.8)	1 (1.7)	13 (22.4)	0 (0.0)	4 (6.9)	30 (51.7)	8 (13.8)	16 (27.6)
85 and over	Total	176	40 (22.7)	58 (33.0)	31 (17.6)	0 (0.0)	47 (26.7)	19 (10.8)	52 (29.5)	30 (17.0)	15 (8.5)	60 (34.1)
	Always	62	36 (58.1)	10 (16.1)	5 (8.1)	0 (0.0)	11 (17.7)	16 (25.8)	15 (24.2)	6 (9.7)	9 (14.5)	16 (25.8)
	Sometimes	79	4 (5.1)	44 (55.7)	10 (12.7)	0 (0.0)	21 (26.6)	3 (3.8)	33 (41.8)	13 (16.5)	5 (6.3)	25 (31.6)
	Incapable	35	0 (0.0)	4 (11.4)	16 (45.7)	0 (0.0)	15 (42.9)	0 (0.0)	4 (11.4)	11 (31.4)	1 (2.9)	19 (54.3)



## **Discussion**

We assessed decision-making and communication capacities of 448 persons with dementia aged 65 or above who required assistance and care in Gujo City, Gifu prefecture, Japan for a two-year period. The results suggested that approximately one-third of the people with dementia were capable of making decisions when they required assistance and care, and that they were able to participate in their care decisions.

In general, it is assumed that the desires of people with dementia are difficult to ascertain [3]. Consequently, family caregivers often take the role of surrogate decision maker [13]. For clinically, ethically, and legally appropriate decision-making, however, the participation of the people with dementia is essential. Approximately one-third of people with dementia, who required assistance and care, were capable of making decisions, and approximately 80% were capable of communicating with others in the present study. These results encourage people with dementia to participate in their own care. Since decision-making capacity declined from baseline to almost half at one year and about one-third at two years, earlier efforts have to be made to ensure that the preferences of the persons with dementia are reflected in their care. Even after their decision-making capacity declined, their communication skills can

still be used to help understand what they want. Many of the participants were capable of communicating with others in the present study, and their views could be incorporated into their care. The findings of the present study also pose a challenge regarding how to develop policies that facilitate the participation of the person with dementia in his or her care and respect the decision he or she will make [14].

BPSD has been a top priority in dementia care because it is associated with high caregiver burden and a higher rate of institutionalization [15]. People with BPSD had lower decision-making capacity than those without BPSD. The present results indicate an association between decision-making and BPSD and suggest that those with BPSD have decreased decisional capacity due to confusion. Approximately 10% of persons with dementia who are sometimes capable of making decisions or are entirely incapable of making decisions may exhibit improved abilities later on, although this number is small. Time and quality of care might stabilize the confusion of individuals with BPSD, thus improving their conditions. Nurses should be aware of the connections between older people's decision making and their BPSD, and carefully encourage their decision making. Further improvement can be expected in those without BPSD. Appropriate BPSD care may help improve of communication, but further studies are needed in order to identify the cause of this improvement in decisional capacity.

Although dementia care in older adults has mainly focused on aspects of BPSD, such as aggression and wandering, psychological care for the vulnerable person, and musical therapy for stress relief, our research suggests that care based on communication can be provided in people with dementia. The establishment and maintenance of a meaningful relationship between the person with dementia and his or her caregivers is the hallmark of person-centered care [5]. Strong communication skills are required for health care providers to support the decision-making of people with dementia [16].

A higher number was observed in the “always capable of making decisions” category in the older age groups compared with the younger age group. This may be partly because many younger persons require assistance and care under the long-term care insurance scheme due to stroke and that older adults are likely to become recipients due to fall or fracture [3], but a causal relationship should be explored in future studies. Also, the question remains as to why more men than women are incapable of making decisions. The role differences in men and women, association with comorbidity, family and support may be reflected in the results, but these are not proven and should be examined in further studies.

The findings of the present study can be useful for enhancing communication with older adults with dementia, improving their care and protecting their human rights. The findings can also help in increasing public understanding of and policy making to dementia and building a foundation of protection of the

lives of these older adults with dignity. The study revealed that many of older adults with dementia were likely capable of making decisions and communicating with others. Nurses can play vital roles in team care for individuals with dementia. They should identify health needs of these older clients using communication skills as part of their physical and psychological assessments. The nurse should make their explanation carefully, assessing whether her clients understand about the information giving. It is important for nurses to understand non-verbal communication as well as verbal communication. The nurses should praise and assist when their clients have made their decision making, and encourage their participation in care. As an advocate for clients, nurses can also act as the liaison person between their clients and other team members. A majority of the Japanese people show respect for the patients' wish for living [17]. The present study shows a need for ethical considerations to be built for making a consensus between the multidisciplinary team themselves, and also with their clients with dementia, and develop procedure and protocol to facilitate the decision-making process.

The present study was conducted in a community-dwelling sample of older adults with dementia aged 65 and over, who required assistance and care under the long-term care insurance program in one of rural areas in Japan. For this reason, the generalizability of the findings is limited. Further, all the assessment scales fit with the Japanese national criteria under the long-term care insurance program. The

Mini-Mental State Examination (MMSE), which measures overall cognition, is widely used for the screening of dementia [18]. In contrast to the MMSE, assessment of the level of dementia in long-term care insurance is not intended to screen dementia but to classify recipients by identifying their cognitive difficulties in daily living and self-care. As dementia is a progressive deteriorating process and the clients can be diagnosed at various stages, the present study had only observed and summarised the process of decision-making and communication capacities in the older clients with dementia after they were required and enrolled for assistance and care. Further study is needed to assess the changes in decision making and communication throughout the entire illness process, including the early phase of dementia and the end-of-life care. Because limited evidence is available, the findings of this study on the changes in decision making and communication abilities over time have provided important implications for dementia care in spite of the above mentioned methodological limitations.

## **Conclusions**

Although people with dementia recognize their need of support, they retain a desire to remain central in the decision-making [15]. The present study reveals that approximately one-third of older adults with dementia are capable of making decisions when they need assistance and care. These findings suggest that we should encourage them to participate in care. However, this proportion will decline over time, and

it is necessary to ensure that their preferences are reflected in care early on. Further, approximately 80% of the older adults with dementia were capable of communicating with others in the present study. The findings highlight the effort that needs to be made to become closer to persons with dementia to listen to their voices in person-centered care.

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