Understanding Treatment Attitudes toward Dementia: Differences among community residents and health care professionals

Hiroaki MIYATA*, Kaoruko AITA[2*], Hiromi SHIRAISHI[3*] and Ichiro KAI[2*]

To examine how the severity of dementia affects attitudes to treatment preferences in a lay group of community residents and a group of medical care professionals who provide direct care to dementia affected patients.

The participants were 259 community residents aged between 40 and 65, and 217 care professionals working at nursing homes or group homes. Respondents were randomly assigned to one of two scenarios involving moderate or severe dementia and each was asked questions about their preferences and attitudes to the employment of eight types of active treatments (ATs) to deal with a newly acquired illness as well as eight types of life-sustaining treatment (LST).

Among the community residents, there were no significant differences in preferences toward any treatment items between the moderate dementia and severe dementia scenarios. Similarly, care professionals showed no significant differences in attitudes toward 15 of the 16 treatment items. The community residents had more negative attitudes than care professionals in attitudes to all types of LST, including four variations of AT that have a good chance of success.

After dementia deprives an individual of decision-making capacity, progress of the disease has little effect on both community residents and care professionals' preferences. When discussing about end-of-life decision-making, care professionals need to be careful about the gaps in perception of good chance treatments with patients.

Key words: end-of-life, decision-making, advance planning, treatment preferences, dementia

I. INTRODUCTION

The number of people with Alzheimer's disease in the United States in the year 2000 was believed to be 4.5 million[1)], and it is projected that the prevalence of the disease will nearly quadruple in the next 50 years[2)]. In Japan, the number of persons with dementia requiring some care or assistance in daily life, reported to be 1.5 million in 2002, is also rising year by year[3)]. Our previous research showed that more than a half of nursing home residents in Japan have difficulties negotiating daily life because of problems related with dementia[4)]. When dementia deprives individuals of decision-making capacity, family and close relatives are often asked to make judgments in lieu of the patient regarding treatment choices. Ethicists have argued that this process is an important way of respecting patient autonomy[5)]. Research conducted to date, however, has repeatedly found that both family members and care professionals show substantial inaccuracy in predicting patients' treatment preferences regarding the use of life-sustaining treatments and technologies[6〜8)]. In addition, as the need to clarify the treatment preferences of terminally ill patients is critical in being able to provide high-quality care at the end of life[9〜12)], this issue is very important for these suffering from dementia. Although Japanese culture values harmonious group consensus and tacit agreement with implicit communication (ishin-denshin), earlier research suggested that Japanese patients' preferences regarding cancer disclosure, willingness to forgo care, and views of advance care planning are shifting toward those found in Western countries[13)].

It has been suggested that patients' preferences regarding treatment options should be based not only on the specific treatments themselves but rather on the outcomes[14,15)]. Results from qualitative[16)] and quantitative studies[17,18)] support the importance of outcomes in determining patients' treatment preferences, and recent research on advance care planning

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[*] Department of Healthcare Quality Assessment, Graduate School of Medicine, University of Tokyo, Japan

[2*] Department of Social Gerontology, School of Health Sciences and Nursing, Graduate School of Medicine, University of Tokyo, Japan

[3*] Toyo University, Faculty of Human Life Design, Japan

indicates that patient' attitudes toward the burden of the treatment and the possible outcomes and their likelihood of success$^{19)}$ should be taken into account. In order to evaluate the effect of disease burden on treatments preferences, the present study posed scenarios with varied burden and possible outcomes for a newly acquired illness and asked respondents about their treatment preferences.

Previous studies have employed a relatively simple definition of dementia which does not take into account when symptoms become severe and patients are unable to participate in making decisions about their treatment and care$^{20\sim22)}$. In this study, we investigated two scenarios of moderate and severe dementia, affecting the patient's clinical condition to the point that they lack decision-making capacity. As lay persons responses toward progress of dementia might differ from these of medical and care professionals because of a lack of direct experience with dementia, we sent the same type of questionnaire to care professionals who treat and care for institutionalized elderly people with dementia. While many studies have suggested differences between the treatment preferences of patients and care professionals$^{23\sim25)}$, to our knowledge no research has been conducted to provede details (e.g. with concrete dementia scenarios) as performed here.

II. METHODS

Survey I
(Community residents as potential patients)

This study was a cross-sectional, stratified random sample survey of the general population aged between 40 and 65 in Japan. As people over 65 years old are epidemiologically more at risk of having dementia, we excluded them from the sample not only because it seemed harmful to ask them about dementia-related matters, but also because there was a possibility that their responses would be affected by existing symptoms. Participants were selected from the list of eligible voters in A ward in Tokyo (which consists of 23 wards). We chose A ward as representative of Tokyo because various social indices such as the proportion of the elderly in the population, the average length of education, and the population growth rate are consistent with the Tokyo averages$^{26)}$. In the sampling, we first randomly selected 20 out of the 120 blocks that constitute A ward, then, selected 444 people aged between 40 and 65 from the local government's residents registry at random. A self-administered blank form questionnaire with a prepaid return envelope was sent via mail to them in March 2004. We sent reminder notices twice. Of the 444, 259 people responded (response rate 58.3%). The 12-page questionnaire was developed in consultation with 5 medical professionals and 30 lay people giving advice from the standpoint of patients. The questionnaire presented a hypothetical scenario asking respondents about their preferences toward certain types of treatments in situations where they have limited capacity to make decisions due to dementia. We created two scenarios involving moderate and severe dementia. Explanation of each condition was based on the Clinical Dementia Rating$^{27)}$ (Appendices). Only one of the two scenarios was randomly assigned to each questionnaire so that each respondent answered questions regarding one situation only (Some community residents received the moderate dementia scenario and others received the severe dementia scenario). Questions were all identical in both scenarios. The questionnaire began with the introduction: "If you acquire another illness while having moderate/severe dementia, would you choose to undergo the following medical treatments?" Respondents were then asked about their preferences toward a total of 8 active treatments (ATs) with varying degrees of burden/chance of success/length of survival to deal with the increasing debility. No specific treatment was mentioned in the 8AT variations, but they were defined by the combination of the following characteristics: burden the AT imposes is low or high, the chance of success is good or poor, and possible outcome in terms of the length of survival is about 6 months when not treated as opposed to over 2 years when treated in one version, less than 1 month when not treated as opposed to about 6 months when treated in another version. Examples of low-burden approaches were described as therapies such as oral administration of medication and intravenous antibiotics. High-burden approaches were described as surgery and medication with possibly severe side effects.

Respondents were also asked about their preferences toward 8 life-sustaining treatments (LSTs): 4 types of LST with two different survival periods. The types of LST included were cardio-pulmonary resuscitation, artificial ventilation, dialysis, and artificial nutrition. Each treatment was considered to prolong the length of survival to over 2 years in one version, and to about 6 months in the other. The scenarios stated that without these LSTs the patient would die shortly. The questions were intended to investigate whether respondents' preferences toward each type of the LSTs would change if the length of survival were different. As for the ATs, in which no treatment was specified, respondents had to address burden, chance of success and survival period, but for the LSTs, the respondents had to address the specific treatments and the length of survival.

The questionnaire also included the Japanese 12

Item version of the General Health Questionnaire (GHQ-12) which is used to assess predisposition and non-psychotic psychiatric illness[28,29]. The Japanese version of GHQ-12 is standardized and widely used[30,31]. In the present sample, the GHQ for Cronbach's $\alpha = 0.83$. For other patient characteristics we included questions regarding age, sex, religion, income, educational background, employment, experiences relating to medical care and experiences relating to dementia.

Survey II (Care professionals)

The survey with health care professionals was a cross-sectional survey of care professionals taking care of the elderly with dementia at randomly sampled nursing homes and group homes across the nation. Respondents included registered nurses and care workers holding government recognized certification. In Jan 2004, a self-administered questionnaire with a prepaid return envelope was sent via mail to 300 nursing homes and 300 group homes. The care professional in charge of providing care in the facility was asked to answer the questionnaire. We sent reminder notices once. Of the 600 care professionals, 328 persons responded (response rate 54.7%). Of the 328 respondents, 71 were registered nurses, 148 were care workers with government recognized certification, 26 were caseworkers with government certification and 83 had other licenses or was unqualified person. To compare treatment preferences between community residents and those who provide hands-on direct care to the elderly, we limited valid respondents to the two major categories: nurses (N=71) and care workers (N=146; two respondents who had both licenses were included in the nurse category).

The questionnaire presented a hypothetical scenario with either moderate or severe dementia, asking health care professionals about their attitudes toward certain types of treatment when patients have a limited decision-making capacity due to dementia. Again only one of the two scenarios was randomly assigned to each questionnaire. Explanation of each condition was the same as for community residents (Appendices). Questions were identical for the two situations. The questionnaire started with the introduction: "If a patient acquires another illness while having moderate/severe dementia, what do you think about giving the following treatment to the patient independent of the policies and practices of the facility that you work in?" Care professionals were then asked about their attitudes toward ATs to deal with the newly acquired illness and LSTs as listed above. They were also asked questions about personal characteristics including age, sex, job title, the type of facility they were working in, and their employment career in dementia care. We also asked respondents about the availability of the LSTs at their facilities.

Statistical Analysis

We described the distributions of the study populations regarding their attitudes toward the treatment options. The Mann-Whitney's U-test and the Fisher's exact test were conducted to determine the differences in respondents' characteristics and treatment preferences between the two scenario groups. We also used the Fisher's test to examine differences between community residents and care professionals' attitudes toward each treatment. To examine the relationship between respondents' characteristics and their preferences or attitudes toward treatments, we used the total score of the LSTs and the ATs with the Range 0-8; for each item, negative attitude=0, positive attitude=1. Mann-Whitney's U-test was used to examine this relationship. All reported P values are two-sided. Statistical analyses were conducted using SPSS Version 13.0E.

III. RESULTS

Table 1 summarizes characteristics of the community residents. The mean age of the 259 people was 52.9 years ± 7.3 years, 54.4% were female and 26.3% had graduated from college. Some 142 completed surveys with the moderate dementia situation, and 117 answered the questions regarding severe dementia situation. There were no significant differences in the characteristics of respondents between the two scenario groups.

Table 1. Characteristics of community residents (N=259)

	Mean	SD	N.A.
Age (yrs)	52.9	±7.3	6
GHQ (total score)	24.5	±4.8	5
	N	**%**	**N.A.**
Sex (female)	141	(54.4)	5
College graduates	68	(26.3)	7
Living alone	38	(14.7)	5
Married	195	(75.3)	5
Living with adult child	98	(37.8)	5
Living with under-age child	76	(29.3)	5
Have experience of care for dementia	56	(13.4)	1
Non religious	200	(77.2)	5

* Non religious are those who do not engage in any religious observances or devotional activities

Table 2 shows the characteristics of the care professionals: 71 nurses and 146 care workers. Of the 217 respondents, 109 answered questions regarding the moderate dementia situation, and 108 answered the questions regarding the severe dementia situation. There were no significant differences in the characteristics of respondents between the two scenario groups. The mean age of the nurses was 48.3 years ± 8.4 years and that of care workers was 40.2 years ± 10.8 ($P<0.001$). Females made up 95.8% of nurses and 67.1% of care workers ($P<0.001$). The mean career period for nurses taking care of elderly people with dementia was 8.2 years ± 6.6 years and that of the care workers was 9.5 ± 6.1 years ($P<0.05$). Regarding the type of facility 62.0% of nurses and 41.8% of care workers worked at nursing homes ($P<0.01$).

Among the community residents, there were no significant differences in preferences toward any treatment items between the respondents answering questions about the moderate dementia and severe dementia scenarios (Table 3, Table 4). Similarly, the care professionals showed no significant differences in attitudes toward 15 of the 16 treatment items between the moderate and severe dementia scenario groups (Table 3, Table 4). Therefore, we combined the data for the moderate and severe dementia scenarios for further analysis.

The distributions of respondents who answered affirmative to undertaking ATs for the newly acquired illness are shown in Table 5. Among the 8 AT variations, the community residents, nursing and care staff showed significant differences in attitudes to four types of ATs, all of which with a good chance of success. Regarding the 8 LST variations, i.e., the four types of LST with two different survival periods, the groups of respondents showed significant differences in attitudes to all of them (Table 6).

There were no significant differences in respondents' characteristics and treatment preferences between the moderate and severe dementia scenarios in community resident and care professional respondents. However, several significant differences in treatment preferences were shown to be dependant on a number of the community residents' characteristics. Community residents who had been married had positive attitudes toward ATs to deal with newly acquired illness ($P<0.01$). Likewise, community residents who had children aged under 20 had positive attitudes toward ATs ($P<0.001$). Meanwhile, community residents aged 50 and over had negative attitudes toward ATs ($P<0.01$) as well as LSTs ($P<0.05$). Community residents who lived alone had negative attitudes toward ATs ($P<0.05$). Community residents who were not religious had negative attitudes toward LSTs ($P<0.001$). There was only one significant difference in care professionals' attitudes toward treatment depending on their characteristics. Care professionals who had a nursing license had negative attitudes toward LSTs ($P<0.001$). Significantly more care professionals at nursing homes had nursing licenses than those at group homes ($P<0.01$), and significantly less care professionals at nursing homes held care worker qualifications than those at group homes ($P<0.05$).

Table 2.　Characteristics of care professionals (N = 217)

		Nurses (n = 71)			Care Workers (n = 146)		
		Mean	SD	N.A.	Mean	SD	N.A.
Age (yr)		48.3	±8.4	2	40.2	±10.8	3
Career in care for elderly with dementia (yr)		8.2	±6.6	3	9.5	±6.1	4
		N	%	N.A.	N	%	N.A.
Sex (female)		68	(95.8)	0	98	(67.1)	0
Job title (director)		14	(22.6)	9	29	(23.8)	24
Facility	Nursing Home	44	(62.0)	0	61	(41.8)	0
	Group Home	27	(38.0)	0	85	(58.2)	0
Life-sustaining treatment available at one's facility	CPR*	46	(64.8)	0	95	(65.1)	0
	Artificial Ventilator	4	(5.6)	0	20	(13.7)	0
	Dialysis	4	(5.6)	0	7	(4.8)	0
	Artificial Nutrition	43	(60.6)	0	73	(50.0)	0

* Cardio Pulmonary Resuscitation

Table 3. Respondents' preferences toward active treatments (ATs)

There were no significant differences between moderate and severe dementia scenario in community residents toward AT variations. There were no significant differences in care professionals toward 7 of the 8 AT variations.

Burden	High	High	High	High	Low	Low	Low	low
Chance of success in the treatment	Poor	Poor	Good	Good	Poor	Poor	Good	Good
Life expectancy success/not treated	6 months /1 month	Over 2 years /6 months	6 months /1 month	Over 2 years /6 months	6 months /1 month	Over 2 years /6 months	6 months /1 month	Over 2 years /6 months
	% (distribution of respondents with positive preferences/attitudes)							
Community residents								
Moderate (n=142)	6 (4.4%)	6 (4.4%)	24 (17.6%)	41 (29.9%)	38 (27.7%)	43 (31.4%)	90 (65.7%)	105 (76.1%)
Severe (n=117)	4 (3.5%)	5 (4.4%)	25 (21.9%)	31 (27.2%)	35 (30.4%)	42 (36.5%)	73 (63.5%)	85 (73.9%)
Fisher's Exact test	*P*=.76	*P*=1.00	*P*=.42	*P*=.68	*P*=.68	*P*=.42	*P*=.79	*P*=.77
Care Professionals								
Moderate (n=109)	8 (7.5%)	8 (7.5%)	36 (33.6%)	66 (61.7%)	27 (25.2%)	44 (41.1%)	87 (81.3%)	105 (98.1%)
Severe (n=108)	1 (1.0%)	3 (2.9%)	30 (28.6%)	60 (57.1%)	21 (20.0%)	36 (34.3%)	86 (81.9%)	104 (98.1%)
Fisher's Exact test	*P*=.04*	*P*=.21	*P*=.46	*P*=.58	*P*=.41	*P*=.324	*P*=1.00	*P*=1.00

* Low-burden approaches were described as therapies such as oral administration of medication and intravenous antibiotics.

** High-burden approaches were described as surgery and medication with possibly severe side effects.

Table 4. Respondents' preferences toward life-sustaining treatments (LSTs)

There were no significant differences in preferences toward any LST items between the respondents answering questions about the moderate dementia and severe dementia scenarios

	Artificial Ventilator	Artificial Ventilator	CPR	CPR	Dialysis	Dialysis	Artificial Nutrition	Artificial Nutrition
Life expectancy	6 months	Over 2 years	6 months	Over 2 years	6 months	Over 2 years	6 months	Over 2 years
	% (distribution of respondents with positive preferences/attitudes)							
Community residents								
Moderate (n=142)	32 (23.2%)	40 (29.0%)	38 (27.5%)	50 (36.2%)	35 (25.4%)	46 (33.3%)	37 (26.8%)	46 (33.3%)
Severe (n=117)	29 (25.0%)	36 (31.0%)	37 (31.9%)	42 (36.2%)	31 (26.7%)	43 (37.1%)	37 (31.9%)	45 (38.8%)
Fisher's Exact test	*P*=.77	*P*=.78	*P*=.49	*P*=1.00	*P*=.87	*P*=.60	*P*=.41	*P*=.43
Care Professionals								
Moderate (n=109)	54 (50.5%)	48 (58.9%)	78 (72.9%)	87 (81.3%)	60 (56.6%)	74 (69.8%)	81 (75.7%)	86 (80.4%)
Severe (n=108)	48 (45.7%)	57 (54.3%)	72 (68.6%)	81 (77.1%)	58 (55.2%)	72 (68.6%)	76 (72.4%)	90 (85.7%)
Fisher's Exact test	*P*=.50	*P*=.58	*P*=.55	*P*=.50	*P*=.89	*P*=.88	*P*=.64	*P*=.36

IV. DISCUSSION

Findings from the respondents in this study suggest the possibility that the severity of dementia had little influence on treatment choices for individuals who are already deprived of the capacity to make decisions. Community residents' lack of experience with dementia had little effect on treatment prefer-

Table 5. Comparisons of attitudes toward AT variations among community residents, nurses and care workers

Burden	High	High	High	High	Low	Low	Low	Low
Chance of success in the treatment	Poor	Poor	Good	Good	Poor	Poor	Good	Good
Length of survival success/not treated	6 months /1 month	Over 2 years /6 months	6 months /1 month	Over 2 years /6 months	6 months /1 month	Over 2 years /6 months	6 months /1 month	Over 2 years /6 months
Community Residents (n=259)	10 (4.0%)	11 (4.4%)	49 (19.6%)	72 (28.7%)	73 (29.0%)	85 (33.7%)	163 (67.4%)	190 (75.1%)
Nurses (n=71)	3 (4.3%)	3 (4.3%)	19 (27.5%)	41 (59.4%)	16 (23.2%)	25 (36.2%)	53 (76.8%)	69 (98.6%)
Care Workers (n=146)	6 (4.2%)	11 (4.4%)	47 (32.9%)	85 (59.4%)	32 (22.4%)	55 (38.5%)	120 (83.9%)	140 (97.9%)
Fisher's exact test	$P=0.98$	$P=0.85$	$P<0.05$	$P<0.001$	$P=0.32$	$P=0.64$	$P<0.001$	$P<0.001$

Table 6. Comparisons of attitudes toward LSTs among community residents, nurses and care workers

	Artifical Ventilator	Artifical Ventilator	CPR	CPR	Dialysis	Dialysis	Artifical Nutrition	Artifical Nutrition
Length of survival	6 months	Over 2 years	6 months	Over 2 years	6 months	Over 2 years	6 months	Over 2 years
Community Residents (n=259)	61 (24.0%)	76 (29.9%)	75 (29.5%)	92 (36.2%)	66 (26.0%)	89 (35.0%)	74 (29.1%)	91 (35.8%)
Nurses (n=71)	22 (31.9%)	28 (40.6%)	41 (59.4%)	48 (69.6%)	27 (39.1%)	39 (56.5%)	46 (66.7%)	53 (76.8%)
Care Workers (n=146)	80 (55.9%)	92 (64.3%)	109 (76.2%)	120 (83.9%)	91 (64.1%)	107 (75.4%)	111 (77.6%)	123 (86.0%)
Fisher's exact test	$P<0.001$	$P<0.001$	$P<0.001$	$P<0.001$	$P<0.001$	$P<0.001$	$P<0.001$	$P<0.001$

ences. Moreover, there were no significant differences between treatment preferences in the event of moderate and severe dementia in the community residents' attitudes to any of the treatment preferences. A similar result was found regarding care professionals attitudes to 15 of the 16 treatment items. Community residents' reactions toward the severity of dementia were similar to these of care professionals who provide direct care to elderly people with dementia. Although this study was scenario based not reflecting the realities of dementia especially for community residents, there were no differences in treatment preferences between community residents who had or had not experienced care for dementia.

As the degree of cognitive status has suggested to be predictive of changes in decision making[32], the existence of patients decisional capacity is an important matter in end-of-life care. However our study showed that after dementia has progressed to a certain stage, further is not regarded as important. In considering the best way to develop an advance-plan, it might be necessary to clarify an individual's wishes in the event that the severity of the dementia deprives the individual of decision-making capacity.

The evaluation of chance of success and burden of treatment was significantly different between community residents and care professionals. Care professionals had more positive attitudes than community residents toward the 4 types of ATs defined as having a good chance of success. Moreover with all LSTs, care professionals also had more positive attitudes than community residents. These results indicate that there is a considerable perception gap between community residents and care professionals regarding treatment that has a good chance of success or prolonging life. Community residents showed negative attitudes to ATs correlating with increasing burden of treatment (Table 5). Since several previous studies on decision-making regarding the treatment of specific diseases[33,34] suggested that patients weigh the burden of the treatment against the possible outcomes, thus people making decisions on their behalf should take the burden of the treatment into account. When discussing end-of-life decision-making, it is necessary that the differences between the patients' view and that of care professionals be acknowledged and taken into account.

There were significant differences among community residents, nurses and care-workers in all attitudes toward LSTs. In addition, nurses had more negative attitudes toward all LSTs than care workers. Regarding artificial nutrition at the end of life, there is no evidence that tube feeding improves any clinically important outcomes, and on the contrary, some previous studies suggested negative effects[35,36]. Nurses' attitudes might reflect this evidence because they are more familiar with the medical knowledge and actual practice in this area than care workers. Some studies in the United States[37,38] also suggested that feeding tube use is associated more with fiscal and organizational features rather than medical benefit. In particular, it is believed that artificial nutrition needs more careful discussion and evaluation than other LSTs when providing it as a treatment option to the elderly with dementia.

Some of the community resident's demographic characteristics including age, marital status and the supporting of an underage child were shown to be associated with positive attitudes toward undergoing treatments to deal with newly acquired illness. As LST preferences of cognitively intact nursing home residents have been found to be stable over 6 months, and with treatment preference patterns moving toward less intervention[39], demographic factors may indicate particular preferences toward treatment toward the end of life. Thus, changes in family structure or patient's aging can be good indicators of the need to reconsider advance planning.

As this study was a cross sectional survey in Japan, these results might not be simply appllicable to other countries. However patients' preferences regarding LSTs in this study (with 20%–40% of respondents desiring treatment) are similar to figures found in studies conducted in the United States[17,22]. In addition, previous research suggests that Japanese patients' preference regarding cancer disclosure, willingness to forgo care, and views of advance care planning are shifting toward those found in Western countries[13]. Though doctors' and institutions' attitudes regarding advance planning differ between Japan, the United States, and other Western countries[40], there is evidence to suggest that there is less variation regarding patients' preferences. We would like to make a couple of comments on the representative-ness of this survey's community residents in Japan. As the response rate for this study was generally good for a general population survey, we believe that the response rate did not significantly affect the overall results obtained. However the sample was limited to residents residing in Tokyo and aged between 40 and 65. As Tokyo is the most condensed and diverse metropolitan area in Japan, further research is needed in order to allow comparison with data collected in rural areas and smaller towns and cities. It is also required to add younger (under the age of 40) and older people (over the age of 65) in further research if we were to consider generalization of the findings.

Respondents' consent and permission to publish

Before completing the questionnaire, respondents were notified of its nature, methods, and use as follows "this study is a piece of academic research, and is being conducted anonymously. You can freely refuse participation. We regard your response as consent to participation in this study." This study met the basic requirements regarding consent and permission to publish.

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Appendices: Explanation of each condition regarding dementia

Scenario 1（Moderate dementia）

Unable to make judgments regarding medical treatment because of Moderate Dementia（only simple chores preserved, very restricted interests poorly maintained, difficulty with time relationships; usually disoriented regarding and time often also place）and requiring assistance in dressing, hygiene keeping of personal effects. None of these symptoms are curable.

Scenario 2（Severe dementia）

Unable to make judgments regarding medical treatment because of Severe Dementia（no significant functions at home, oriented to the person only, severe memory loss; only fragments remain）and requiring much help with personal care; frequent incontinence. None of these symptoms are curable.

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