

## Factors related to the Caregiver's Preferred Place of Death

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### Key Words :

caregiver  
place of death  
care experience

### ABSTRACT

This study aims to clarify the factors related to the choice of the place where a person giving nursing care wishes to die and to examine better ways of supporting such persons. In 2009, a questionnaire survey was performed among caregivers of patients who used a home-visit nursing station in prefecture A, and 375 caregivers were selected as the subjects of the study. In this survey, 109, 149, and 117 subjects answered "at home" (29.1%), "not sure" (39.7%), and "in hospital or facility" (31.2%) as their preferred place of death. In contrast to the subjects who answered "at home," many subjects who answered "not sure" had no collaborator or no experience of terminal care at home. Moreover, many subjects who answered "in hospital or facility" had male patients and had no collaborator or no experience of terminal care at home. Therefore, to ensure that caregivers were aware of terminal care at home during their care experiences, a system by which home-visit nursing services can be easily pursued without collaborators should be established, and opportunities to increase the understanding of terminal care at home should be provided.

### I. Introduction

Following the increase in the number of elderly persons, Japan has become a super-aged society and terminal care has become an important issue.<sup>1)</sup>The Ministry of Health, Labour and Welfare (MHLW)<sup>2)</sup> aims at "providing appropriate terminal care for patients while respecting their intentions" and attempts to increase the ratio of death at home to 40% by 2025. Regarding home-visit nursing care, the revision of medical repayment standards in the fiscal year 2008 increased the fee for terminal care and added an extra fee to a new system of providing 24-hour services. Thus, Japan's policies aim to improve home-related services and tend to attach importance to death at home.<sup>3)</sup>

Previous studies on death at home reported that the ratio of patients who died at home was high when patients expressed an intention to die at home or their families expressed this preference for the patient.<sup>4), 5)</sup>Regarding the consciousness of caregivers, it was pointed out that although the satisfaction level of caregivers who had provided terminal care at home was high,<sup>6), 7)</sup> they felt anxious about giving terminal care at home and their physical and mental burdens were heavy.<sup>8)-13)</sup> Factors that enabled death at home were reported to be "doctors' visit to patients," "24-hour home-visit nursing care services," and "both patients' and caregivers' desires for death at home."<sup>14), 15)</sup>

The MHLW conducted the Investigation into Terminal Care<sup>16)</sup> on Japanese nationals in 2010. Only 10.9% of the subjects wanted to receive medical treatment at home until their deaths if they had no chance to be cured and were approaching death, and as many as 66.2% answered that receiving medical treatment at home was difficult to realize. When asked to provide reasons for their responses, 79.5% of the subjects reported that "receiving medical treatment at home is a burden on a patient's family who takes care of the patient" and 54.1% mentioned that "there is uneasiness in treatment when the condition of a patient suddenly changes." Hatano<sup>17)</sup> reported that the ratio of persons who worried about their families' trouble and inconvenience and answered "I do not

care about my place of death," although wanting to die at home, was high. In other words, people who mentioned that receiving terminal care at home would be difficult had considered the burden on caregivers and forewent terminal care at home although they wanted it. Moreover, these persons are anxious about terminal care at home because emergency measures cannot be taken, unlike in a hospital.

In order to provide terminal care for patients while respecting their intentions in the future, it is necessary to establish local communities where persons who want to die at home can fulfill their wishes. It is also important to examine how caregivers who are actually involved in care at home think about problems with terminal care while providing care. As the satisfaction felt when providing terminal care at home is reported to be high<sup>18), 19)</sup>, the number of caregivers who want to die at home may increase depending on their care experience. However, it is still unknown how caregivers' care experience affects their preferred place of death.

Thus, the aim of the present study is to elucidate how caregivers who have experienced care think about their place of death, what factors are related to the selection, and how to support care.

### II. Methods

#### 1. Subjects

The present study distributed questionnaires to 1,060 caregivers (subjects in this study) of users (patients in this study) at 30 home-visit nursing stations (out of 38) in prefecture A and collected answers from 651 caregivers (a response rate of 61.4%). We considered that caregivers aged above 40 would find it easier to think about their preferred place of death, so this study selected caregivers aged above 40. Of the selected caregivers, 375 caregivers (an effective response rate of 35.4%) who filled in the necessary items and satisfied the following conditions: (1) they were the patients' spouse, children, or daughters-in-law; and (2) the patients were aged above 40, were analyzed.

In addition, this study was performed as part of an investigation on the satisfaction level of home-visit nursing station users.

#### 2. Survey

The questionnaires were distributed by nurses through

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home-visit nursing stations in August 2009. The caregivers mailed the completed questionnaires to researchers.

Regarding the patients, "age," "gender," "nursing care level," "period spent using home-visit nursing services," "principal disease," "dementia," and "use of services" were set as items.

Regarding the caregivers, "preferred place of death," "age," "gender," "family relationship," "working," "period of care," "care level in daytime," "care level in nighttime," "collaborator (who assist caregivers)," "subjective feeling of health," and "experience of terminal care" were surveyed. Regarding attitudes toward care, "anxiety about the future" and "caregiver burden" were set as negative items, "pleasure of spending time with patient" and "sense of fulfillment by care" were set as positive items, and these items were evaluated using a 5-point scale. The effect and satisfaction level of home-visit nursing services were also evaluated using a 4-point scale. The 5-point scale for "anxiety about the future" comprised "always," "frequently," "sometimes," "infrequently," and "not at all." The answers of "always," "frequently," and "sometimes" were determined to belong to a "yes" group and those of "infrequently" and "not at all" were determined to belong to an "others" group. The 5-point scale for "caregiver burden" comprised "serious," "considerable," "moderate," "little," and "not at all." The answers of "serious" and "considerable" were determined to belong to a "heavy" group and those of "moderate," "little," and "not at all" were determined to belong to an "others" group. The 4-point scale for "pleasure of spending time with patient" and "sense of fulfillment by care" comprised "always," "sometimes," "seldom," and "not at all." The answers of "always" and "sometimes" were determined to belong to a "yes" group and those of "seldom" and "not at all" were determined to belong to a "no" group.

The 4-point scale for the effect and satisfaction level of home-visit nursing services comprised "high," "moderate," "little," and "not at all." Since the number of answers of "high" was large, the answers of "high" were determined to belong to an "effective" group and those of "moderate," "little," and "not at all" were determined to belong to an "other" group.

"Care experience" in this study included caregivers' mental, physical, and care conditions that were felt during providing care.

### 3. Analysis

Caregivers' preferred places of death were classified into three groups of "at home," "not sure," and "in hospital or facility," and the relationships between these three places and the survey items were analyzed using the chi-square ( $\chi^2$ ) test.

In the  $\chi^2$  test, a difference at the 10% significance level was observed in the question items related to care experience and the gender and age of the patients and caregivers. Subsequently, multinomial logistic regression analysis was performed, in which these items were forcedly entered as moderator and independent variables and the caregivers' preferred places of death were used as dependent variables to obtain the odds ratio regarding the caregivers' preferred places of death. In the analysis, "at home" was used as a standard for the dependent variables, and the values of correlation coefficients among the forcedly entered items were in a range of  $\pm 0.502$ . The analysis was conducted using SPSS 18.0 for Windows.

### 4. Ethical considerations

In the survey, the anonymity of caregivers was secured such that caregivers anonymously filled in the questionnaires and directly sent them to researchers by mail using return envelopes. We explained the following matters to caregivers in writing: (1) the purpose and method of the survey; (2) caregivers who returned the questionnaires were regarded as having consented to the survey; (3) if caregivers refused to answer the questionnaires, they would suffer no disadvantages in health care services afterward; and (4) caregivers who refused to answer the questionnaires did not need to send them back. The present study was performed after being approved by the Ethics Committee, Toyama College of Welfare Science.

## III. Results

### 1. Ratios of caregivers' preferred places of death

Regarding caregivers' preferred places of death, 109 caregivers answered "at home" (29.1%), 149 answered "not sure" (39.7%) and 117 answered "in hospital or facility" (31.2%).

### 2. Relationships between caregivers' preferred places of death and patient attributes (Table 1)

The average age of the patients was  $79.8 \pm 10.8$  years. Of the 375 patients, 170 were men (45.3%), 227 patients (60.5) were classified as receiving a high level of nursing care, and 156 patients (41.6%) suffered from cerebrovascular disease. No significant difference was observed in the distribution of the three groups between the caregivers' preferred places of death and patient attributes.

### 3. Relationships between caregivers' preferred places of death and caregiver attributes (Table 2)

The average age of the caregivers was  $65.8 \pm 10.2$  years. Of the 375 caregivers, 104 were men (27.7%). The  $\chi^2$  test found significant differences in the distribution among the three groups between the caregivers' preferred places of death and items of "age," "family relationship," "working," "collaborator," and "experience of terminal care."

Regarding preferred places of death, the majority of caregivers aged below 65 years answered "not sure" (46.6%) while the majority of caregivers aged above 65 years answered "at home" (35.5%). When "family relationship" was "spouse," many caregivers answered "at home" (34.7%). When "family relationship" was "child" and "daughter-in-law," the majority of caregivers answered "not sure." When "work" was "yes," many caregivers answered "not sure" (48.6%). When "collaborator" was "yes," many caregivers answered "not sure" (38.3%) as well. The majority of caregivers who had had experience of terminal care preferred to die at home (45.6%). When "experience of terminal care" was "no," the majority of caregivers answered "not sure" (41.4%).

No significant difference was observed in the distribution among the three groups between caregivers' preferred places of death and items of "gender," "period of care," "daytime care level," "nighttime care level," and "subjective feeling of health."

**Table 1. Relationships between caregivers' preferred places of death and patient attributes**

n = 375 Unit: person (%)

Item and category	Total number	Caregivers' preferred places of death			$\chi^2$ test
		At home	Not sure	In hospital or facility	
Total number	375 (100.0)	109 (29.1)	149 (39.7)	117 (31.2)	
Age	79.8 ± 10.8 (46–103)				
Below 65 years old	33 (100.0)	9 (27.3)	16 (48.5)	8 (24.2)	n.s.
Above 65 years old	342 (100.0)	100 (29.2)	133 (38.9)	109 (31.9)	
Gender					
Male	170 (100.0)	51 (30.0)	61 (35.9)	58 (34.1)	n.s.
Female	205 (100.0)	58 (28.3)	88 (42.9)	59 (28.8)	
Nursing care level					
Serious	227 (100.0)	65 (28.6)	94 (41.4)	68 (30.0)	n.s.
Others	148 (100.0)	44 (29.7)	55 (37.2)	49 (33.1)	
Duration of use of home-visit nursing services <sup>†</sup>					
Below 2 years	181 (100.0)	56 (30.9)	66 (36.5)	59 (32.6)	n.s.
Above 2 years	194 (100.0)	53 (27.3)	83 (42.8)	58 (29.9)	
Principal disease					
Cerebrovascular disease	156 (100.0)	45 (28.8)	66 (42.3)	45 (28.8)	n.s.
Others	219 (100.0)	64 (29.2)	83 (37.9)	72 (32.9)	
Dementia					
Yes	90 (100.0)	27 (30.0)	32 (35.6)	31 (34.4)	n.s.
No	285 (100.0)	82 (28.8)	117 (41.1)	86 (30.2)	

[Note] n.s.: not significant

† Period of using home-visit nursing services is divided into two parts according to the median.

**Table 2. Relationships between caregivers' preferred places of death and caregiver attributes**

n = 375 Unit: person (%)

Item	Category	Total number	Caregivers' preferred places of death			$\chi^2$ test
			At home	Not sure	In hospital or facility	
Total number		375 (100.0)	109 (29.1)	149 (39.7)	117 (31.2)	
Age		65.8 ± 10.2 (40–89)				
	Below 65 years old	178 (100.0)	39 (21.9)	83 (46.6)	56 (31.5)	**
	Above 65 years old	197 (100.0)	70 (35.5)	66 (33.5)	61 (31.0)	
Gender						
	Male	104 (100.0)	36 (34.6)	42 (40.4)	26 (25.0)	n.s.
	Female	271 (100.0)	73 (26.9)	107 (39.5)	91 (33.6)	
Family relationship						
	Spouse	196 (100.0)	68 (34.7)	67 (34.2)	61 (31.1)	**
	Child	114 (100.0)	28 (24.6)	55 (48.2)	31 (27.2)	
	Daughter-in-law	65 (100.0)	13 (20.0)	27 (41.5)	25 (38.5)	
Work						
	Yes	109 (100.0)	27 (24.8)	53 (48.6)	29 (26.6)	#
	No	266 (100.0)	82 (30.8)	96 (36.1)	88 (33.1)	
Period of care <sup>†1</sup>						
	Below 4 years	184 (100.0)	59 (32.1)	64 (34.8)	61 (33.2)	n.s.
	Above 4 years	191 (100.0)	50 (26.2)	85 (44.5)	56 (29.3)	
Daytime care level <sup>†2</sup>						
	Continuous care	262 (100.0)	75 (28.6)	98 (37.4)	89 (34.0)	n.s.
	Others	113 (100.0)	34 (30.1)	51 (45.1)	28 (24.8)	
Nighttime care level <sup>†2</sup>						
	Continuous care	225 (100.0)	66 (29.3)	90 (40.0)	69 (30.7)	n.s.
	Others	150 (100.0)	43 (28.7)	59 (39.3)	48 (32.0)	
Collaborator						
	Yes	290 (100.0)	95 (32.8)	111 (38.3)	84 (29.0)	**
	No	85 (100.0)	14 (16.5)	38 (44.7)	33 (38.8)	
Subjective feeling of health						
	Healthy	267 (100.0)	78 (29.2)	110 (41.2)	79 (29.6)	n.s.
	Unhealthy	108 (100.0)	31 (28.7)	39 (36.1)	38 (35.2)	
Experience of terminal care						
	Yes	90 (100.0)	41 (45.6)	31 (34.4)	18 (20.0)	***
	No	285 (100.0)	68 (23.9)	118 (41.4)	99 (34.7)	

[Note] #: p &lt; 0.1, \*\*: p &lt; 0.01, \*\*\*: p &lt; 0.001, n.s.: not significant

†1: Period of care is divided into two parts according to the median.

†2: Others in care level refer to "sometimes," "rare," and "not at all."

## 4. Relationship between caregivers' preferred places of death and use of services (Table 3)

When "home-visit bathing service" was "yes," the majority of the caregivers answered "at home" (38.2%). When "home-visit bathing service" was "no," the majority of the caregivers answered "not sure" (41.6%). When "short stay" was "yes" and "no," the majority of the caregivers answered "not sure" (41.5%) and (38.9%), respectively. No significant difference was observed in the distribution among the three groups between caregivers' preferred places of death and the use of other services.

## 5. Relationship between caregivers' preferred places of death and attitudes toward care (Table 4)

When "pleasure of spending time with patient" was "yes" and "no," the percentages of caregivers who answered "at home" and "not sure" were 36.2% and 43.4%, respectively. When "sense of fulfillment by care" was "yes" and "no," the percentage of caregivers who answered "not sure" and "at home" were 36.8% and 43.6%, respectively. No significant difference was observed in the distribution among the three groups between caregivers' preferred places of death and "anxiety about the future" and "caregiver burden."

## 6. Relationship between caregivers' preferred places of death and the effect and satisfaction level of home-visit nursing services

No significant difference was observed in the distribution among the three groups between caregivers' preferred places of death and the effect and satisfaction level of home-visit

**Table 3. Relationship between caregivers' preferred places of death and use of services**

n = 375 Unit: person (%)

Item and category	Total number	Caregivers' preferred places of death			$\chi^2$ test
		At home	Not sure	In hospital or facility	
Total number	375 (100.0)	109 (29.1)	149 (39.7)	117 (31.2)	
Home help					
Yes	121 (100.0)	41 (33.9)	48 (39.7)	32 (26.4)	n.s.
No	254 (100.0)	68 (26.8)	101 (39.8)	85 (33.5)	
Home-visit bathing service					
Yes	89 (100.0)	34 (38.2)	30 (33.7)	25 (28.1)	#
No	286 (100.0)	75 (26.2)	119 (41.6)	92 (32.2)	
Home-visit rehabilitative service					
Yes	99 (100.0)	30 (30.3)	41 (41.4)	28 (28.3)	n.s.
No	276 (100.0)	79 (28.6)	108 (39.1)	89 (32.2)	
Day care					
Yes	173 (100.0)	42 (24.3)	75 (43.4)	56 (32.4)	n.s.
No	202 (100.0)	67 (33.2)	74 (36.6)	61 (30.2)	
Day care with rehabilitation service					
Yes	72 (100.0)	23 (31.9)	30 (41.7)	19 (26.4)	n.s.
No	303 (100.0)	86 (28.4)	119 (39.3)	98 (32.3)	
Short stay					
Yes	118 (100.0)	26 (22.0)	49 (41.5)	43 (36.4)	#
No	257 (100.0)	83 (32.3)	100 (38.9)	74 (28.8)	
Home-visit medical service					
Yes	173 (100.0)	53 (30.6)	70 (40.5)	50 (28.9)	n.s.
No	202 (100.0)	56 (27.7)	79 (39.1)	67 (33.2)	
Home-visit guidance on drug management					
Yes	9 (100.0)	2 (22.2)	4 (44.4)	3 (33.3)	n.s.
No	366 (100.0)	107 (29.2)	145 (39.6)	114 (31.1)	
Meal on wheel					
Yes	8 (100.0)	2 (25.0)	2 (25.0)	4 (50.0)	n.s.
No	367 (100.0)	107 (29.2)	147 (40.1)	113 (30.8)	
Housing renovation					
Yes	58 (100.0)	18 (31.0)	17 (29.3)	23 (39.7)	n.s.
No	316 (100.0)	91 (28.8)	132 (41.8)	93 (29.4)	
Welfare support					
Yes	276 (100.0)	77 (27.9)	114 (41.3)	85 (30.8)	n.s.
No	99 (100.0)	32 (32.3)	35 (35.4)	32 (32.3)	

[Note] #:  $p < 0.1$ , n.s.: not significant

**Table 4. Relationship between caregivers' preferred places of death and attitudes toward care**

n = 375 Unit: person (%)

Item and category	Total number	Caregivers' preferred places of death			$\chi^2$ test
		At home	Not sure	In hospital or facility	
	375 (100.0)	109 (29.1)	149 (39.7)	117 (31.2)	
Anxiety about the future					
Yes	203 (100.0)	64 (31.5)	75 (36.9)	64 (31.5)	n.s.
Others	172 (100.0)	45 (26.2)	74 (43.0)	53 (30.8)	
Caregiver burden					
Heavy	135 (100.0)	37 (27.4)	52 (38.5)	46 (34.1)	n.s.
Others	240 (100.0)	72 (30.0)	97 (40.4)	71 (29.6)	
Enjoy spending time with patient					
Yes	163 (100.0)	59 (36.2)	57 (35.0)	47 (28.8)	*
No	212 (100.0)	50 (23.6)	92 (43.4)	70 (33.0)	
Sense of fulfillment from providing care					
Yes	212 (100.0)	75 (35.4)	78 (36.8)	59 (27.8)	**
No	163 (100.0)	34 (20.9)	71 (43.6)	58 (35.6)	

(Note) \*:  $p < 0.05$ , \*\*:  $p < 0.01$ , n.s.: not significant**Table 5. Factors related to caregivers' selection of preferred place of death**

n = 375

Item	"Not sure" instead of "at home"	Odds ratio	95% confidence interval		p value	"In hospital or facility" instead of "at home"	Odds ratio	95% confidence interval		p value
			Lower limit	Upper limit				Lower limit	Upper limit	
Patient's age	<65 years/>65 years	1.605	0.521	4.945	n.s.	<65 years/>65 years	0.804	0.229	2.826	n.s.
Patient's gender	Male/Female	1.390	0.737	2.621	n.s.	Male/Female	2.133	1.079	4.217	*
Home-visit bathing service	No/Yes	0.611	0.328	1.138	n.s.	No/Yes	1.512	0.782	2.926	n.s.
Short stay	No/Yes	1.211	0.661	2.217	n.s.	No/Yes	0.717	0.382	1.344	n.s.
Caregiver's age	<65 years/>65 years	1.250	0.583	2.676	n.s.	<65 years/>65 years	1.246	0.553	2.811	n.s.
Caregiver's relationship	Child/Spouse	0.463	0.165	1.299	n.s.	Child/Spouse	0.357	0.121	1.051	n.s.
	Daughter-in-law/Spouse	1.007	0.430	2.355	n.s.	Daughter-in-law/Spouse	0.571	0.233	1.403	n.s.
Caregiver's work	No/Yes	0.779	0.416	1.456	n.s.	No/Yes	1.179	0.589	2.364	n.s.
Collaborator	No/Yes	2.475	1.196	5.128	*	No/Yes	2.646	1.250	5.587	*
Experience with terminal care	No/Yes	2.198	1.263	4.000	*	No/Yes	3.484	1.764	6.849	***
Enjoy spending time with patient	No/Yes	1.655	0.927	2.954	n.s.	No/Yes	1.252	0.679	2.307	n.s.
Sense of fulfillment from providing care	No/Yes	1.268	0.695	2.314	n.s.	No/Yes	1.591	0.844	3.000	n.s.

[Note] \*:  $p < 0.05$ , \*\*\*:  $p < 0.001$ , n.s.: not significant  
Multinomial logistic regression analysis (forced entry)

nursing services.

#### 7. Factors related to caregivers' preferred place of death (Table 5)

Caregivers who had selected "not sure" instead of "at home" were related to items of "collaborator" and "experience of terminal care. The caregivers who had selected "in hospital or facility" instead of "at home" were related to items of "patient's gender," "collaborator," and "experience of terminal care."

For caregivers who had answered "no" to "collaborator," the odds ratio of those who selected "not sure" instead of "at home" was 2.475 (95% confidence interval [1.196, 5.128]), and that of those who selected "in hospital or facility" instead of "at home" was 2.646 (95% confidence interval [1.250,

5.587]). In the case where caregivers had answered "no" to "experience of terminal care," the odds ratio of those who selected "not sure" instead of "at home" was 2.198 (95% confidence interval [1.263, 4.000]), and that of those who selected "in hospital or facility" instead of "at home" was 3.48 (95% confidence interval [1.764, 6.849]). For caregivers who had answered "male" to "patient's gender," the odds ratio of those who selected "in hospital or facility" instead of "at home" was 2.133 (95% confidence interval [1.079, 4.217]).

#### IV. Discussion

##### 1. Caregivers' preferred places of death

In this study, approximately 30%, 30%, and 40% of the

caregivers selected "at home," "in hospital or facility," and "not sure" as their preferred places of death, respectively.

The investigation into terminal care<sup>20)</sup> conducted by the MHLW on Japanese nationals revealed that 10.9% and 4.4% of the subjects preferred "at home" and "not sure" as their places of death, respectively. The present study cannot be simply compared with the investigation conducted by the MHLW because of different question items. However, it was considered that since the subjects of the present study were caregivers who had actually provided care at home, many of them preferred their homes as their place of death. In a study conducted by Araki et al.<sup>21)</sup> in 2005, 45% of caregivers preferred to die at home. However, Araki et al. provided only two options: "at home" and "in hospital or facility." In the present study, we added "not sure." Because of this addition, caregivers who were unable to choose might have selected "not sure" although they might have preferred "at home" or "in hospital or facility." Therefore, in the present study, the ratio of caregivers who selected "at home" as their preferred place of death was low.

Alfons Deeken<sup>22)</sup> described the necessity of death education (1986). Miyazaki<sup>23)</sup> mentioned in 2008 that "the keyword for terminal care in residential facilities is preparation. Since death is inevitable, how to spend time till one's dying day is important. The role of the surrounding people of a person is to support the person to accomplish self-realization." In the future, those who are involved in terminal care, such as care managers and service providers, may be requested to not only support patients but also take part in caregivers' preparation for death. In the process of preparing for death, caregivers seriously think about their lives and deaths through their care experiences and discuss their preferred places of death with their families.

## 2. Factors related to caregivers' preferred place of death

Many caregivers who selected "not sure" instead of "at home" had no collaborator or experience of terminal care. Many caregivers who selected "in hospital or facility" instead of "at home" had male patients, no collaborator, and no experience of terminal care.

Therefore, having a collaborator is an important factor in influencing caregivers' preference of death at home. Ueda<sup>24)</sup> reported in 2004 that "even after the Long-Term Care Insurance Act was enforced, patients' families are still fatigued with care, and care at home mainly depends on families' care capabilities." Washio<sup>25)</sup> reported in 2005 that "the ratio of caregivers suffering from depression has not largely decreased since the Long-Term Care Insurance Program was introduced five years ago." Therefore, the caregiver burden does not seem to have reduced even after the introduction of the Long-Term Care Insurance Program. In the present study, caregivers' selection of preferred place of death was not related to "caregiver burden" and "anxiety about the future," but strongly related to having a collaborator.

Following the decrease in the number of family members living together, one-person and couple-only households are predicted to be more common than ever. Muramatsu<sup>26)</sup> proposed in 2006 that "ideas that care of a person should be taken by his/her family and a person who cannot live alone should be institutionalized are out-of-date. Mutual-aid houses are to be prepared using vacant houses, to where neighbors, nurses, and volunteers visit on occasions." Thus,

the consciousness of citizens needs to be changed from "given medical and welfare services" to "self-determination of their last breath." It is also considered necessary to set up networks in which caregivers can use local resources by themselves and to establish local communities where collaborators are easy to find.

Therefore, it is important to examine how to improve the quality of care services and to build a system in which persons without collaborators in their families and relatives feel that they could die at home in peace.

The present study revealed that experience of terminal care is an important factor that influences caregivers' preference to die at home. Although the burden on caregivers who had experienced terminal care was heavy<sup>27)-32)</sup>, their level of satisfaction was also high<sup>33), 34)</sup>. Therefore, experience of terminal care was considered an important opportunity for caregivers to think about their death. It was suggested that caregivers who had experienced terminal care preferred to select terminal care at home. In the future, it will be necessary to support patients' families such that they perceive that they have sufficient support in terminal care.

Many caregivers who took care of male patients selected "in hospital or facility" as their preferred place of death. These caregivers were mainly women (wives, daughters, and daughters-in-law). The reason for selecting "in hospital or facility" instead of "not sure" was probably because they strongly felt difficulty in providing terminal care at home. Caregivers who took care of male patients in the present study might have made their choices as such because they think that receiving medical treatment at home is a burden on the patient's family and that there would be inconvenience in treatment when the condition of a patient suddenly changes; these were extracted as reasons for the factor "receiving medical treatment at home was difficult to realize" in the investigation into terminal care conducted by the MHLW<sup>35)</sup>. However, the present study could not elucidate such a relationship. In the future, it is necessary to examine why taking care of male patients decreases the number of caregivers who want to die at home.

## V. Conclusion

Approximately 30% and 40% of the caregivers selected "at home" and "not sure," respectively, as their preferred places of death. There is a possibility that after experiencing care, although the ratio of caregivers who select "at home" increases, that of caregivers who select "not sure" also increases.

Having no collaborator, no experience of terminal care, and a male patient were factors that influenced the selection of "not sure" and "in hospital or facility" instead of "at home." Therefore, it is important to help caregivers be aware of terminal care at home during their care experience, to establish a system in which home-visit nursing services can be easily pursued without collaborators, and to provide opportunities to increase the understanding of terminal care at home.

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