

Original Article

**Factors influencing the preferred place of death in  
community-dwelling elderly people in Japan**

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*Conflict of Interest Statement:*

All contributing authors declare no conflict of interest.

## **Abstract**

**Background:** To investigate factors influencing the preferred place of death among community-living elderly people in Japan in relation to personal attributes, health status, self-rated health, and social capital indicators.

**Methods:** A self-report questionnaire survey was conducted between July and September 2009 on a total of 238 elderly people aged  $\geq 65$  years living in Nagasaki Prefecture. Subjects were either members of a social club for the elderly, individuals undergoing special health checkups, or participants of health workshops held by cities. A total of 178 subjects who provided complete responses (79 men, 99 women) were analyzed.

**Results:** Half or more of the subjects (men: 68.4%, women: 52.5%) indicated home as their preferred place of death. Multiple logistic regression analysis showed that good self-rated health (odds ratio (OR): 2.6, 95% confidence interval (95% CI): 1.2–5.7,  $p=0.013$ ), participation in volunteer activities (OR: 2.0, 95% CI: 1.0–3.8,  $p=0.038$ ) and the spouse as the preferred caregiver (OR: 2.5, 95% CI: 1.3–4.8,  $p=0.007$ ) were associated with home as the preferred place of death.

**Conclusion:** It is necessary to consider individual preferences and public health strategies in order to enable elderly people to receive suitable and comfortable end-of-life care in their preferred location.

**Key Words:** end-of-life care, place of death, social capital

## **Introduction**

As the population in Japan continues to age at a rapid pace, the number of deaths is expected to increase. In an annual report for fiscal 2009, Japan showed the rate of deaths occurring at home was only 12.4%, and the rate has plateaued since 1990. Nevertheless, hospital stays are being shortened due to policy decisions based on financial constraints, meaning that more and more patients will likely spend the end-of-life period at home. As a result, ensuring that an individual has a suitable and comfortable death at home has emerged as a problem not only for individuals, but also for public health.

Fulfilling a patient's end-of-life decisions is essential in providing proper care in the end-of-life period. End-of-life preferences include financial decisions, medical decisions and care options. The preference for place of death is an important wish associated with care options.<sup>1-3</sup> Providing support that enables patients to spend the end-of-life period in their preferred place is an important part of enhancing the quality of end-of-life care. Discrepancies between the preferred and actual place of death have attracted a great deal of attention.<sup>4,5</sup> In a study of the general population in Australia, 70% of respondents preferred their own home as their place of death, but only 14% of cancer deaths actually were at home.<sup>6</sup> Factors that affected the number of deaths at home were

reported to be age, causative diseases of death, sex, education, family situation, living conditions and area of residence.<sup>7-10</sup> In a Japanese study, an important factor for dying at home was the preference expressed by the patient, the patient's family and medical staff.<sup>11</sup> Another study in Japan showed the most significant determining factor associated with death at home was that both the caregiver and patient had preferred home as the place of death.<sup>12</sup> These studies indicated that not only patient characteristics but also communication between patients and their families and caregivers affected the actual place of death.

In recent years, social scientists have observed that social networks can have powerful effects on health.<sup>13</sup> Assessing the quality and quantities of social networks was difficult without a useful index; therefore, economic scientists analyzed individual human performance indicators such as income, employment and ability of production and skills, and named these indicators "human capital".<sup>14</sup> Helliwell and Putnam analyzed the quality and quantities of community social networks using an index of "social capital (SC)",<sup>15</sup> which is based on a fundamental concept encompassing "trust," "rules," and "networks" for promoting cooperative behavior among individuals. It was reported that SC was associated with mortality,<sup>12, 16</sup> physical activity,<sup>17, 18</sup> mental health<sup>19</sup> and self-rated health.<sup>20-24</sup>

There are growing numbers of older people living alone who require assistance and nursing care. In order for a person to achieve their preferred end-of-life care, it is important for communities as a whole to provide them with support. Clarifying the factors that affect place of death preference by older people can help improve the quality of end-of-life care. However, research on this topic is insufficient. The present study examines the factors that influence the preferred place of death for community-living elderly people from the perspectives of personal attributes, health status, subjective health views and the SC index.

## **Materials and methods**

A self-administered questionnaire survey was conducted between July and September 2009 on 238 residents of Nagasaki Prefecture aged  $\geq 65$  years. Subjects were either members of a seniors' club, people receiving health check-ups or participants in a city-run health class. Excluding incomplete responses, data from 178 subjects (79 men, 99 women) were analyzed.

The protocol of this study was approved by the Ethics Committee at the Nagasaki University Graduate School of Biomedical Sciences. The research aims were explained

orally to the subjects prior to beginning the study and all subjects gave written informed consent.

Survey questions were designed to obtain socio-demographic characteristics (sex, age, family structure, length of residence in their current home, residence type, presence/absence of work, experience of death of someone living with them, religion, and presence/absence of an illness that requires regular hospital visits), preferred place of death with four response options (medical institution, long-term care facility, home or other), individual self-rated health with four response options (good, fair, not very good and poor), local healthcare (comfort level and worry about medical costs), core insights about SC and preferred terminal healthcare (preferred caregiver and possibility of spending the end-of-life period at home).

We collected information on both cognitive SC (trust of people in the community) and structural SC (number of neighborhoods interacted with and participation in volunteer groups)<sup>18</sup> by asking the questions: “Generally speaking, would you say that most people in your community can be trusted?” for trust of people in the community; “How many associations do you have with your neighbors?” for the neighborhoods interacted with; and “Are you currently involved in volunteer groups (community development, welfare of the aged or disabled, child rearing, sports instruction,



beautification, crime and fire prevention, environment, international cooperation, advocating or other)?” for participation in volunteer groups.

We analyzed local and preferred terminal health care with these questions: “If you or a family member became ill, would you (or your family member) feel comfortable receiving treatment in this region?” for comfort level concerning local healthcare; “Are you worried about future medical costs?” for worry about medical costs; “If you come to require care, who would you most like to receive care from?” for preferred caregiver; and “If you preferred to spend your final days at home, do you think it would be possible to do so?” for possibility of spending the end-of-life period at home.

All statistical analyses were performed using SPSS for Windows Version 11.0 (SPSS Japan, Tokyo, Japan). Answers to questions with a 4-point scale were dichotomized. Subjects who stated their home as the preferred place of death were allocated to a “home group” and all other subjects were allocated to a “non-home group.” Chi-square tests were used for categorical variables. A multiple logistic regression model for the choice of home as the preferred place of death was constructed with  $P < 0.20$  as the entry criterion. The best fitting model was selected based on Akaike’s information criteria (AIC), with lower AIC values indicating a better model fit. Results are presented as odds ratios (ORs) with 95% confidence intervals (95% CI).

## Results

The mean age of subjects was 75.8 years for men and 74.2 years for women. Mean length of residence in their current home was 34.0 years for men and 32.7 years for women. The most common family structure was a two-person household made up of a married couple. About 70% of men and women had an illness that required regular visits to the hospital (Table 1).

Both men and women preferred home as the place of death (Table 2); however, the prevalence was significantly higher among men than women (men: 68.4%, women: 52.5%,  $p=0.045$ ). Since significant sex differences were found in the questionnaire items of family structure and experience of death of someone living with them (Table 1), we conducted further analyses on the relationship of these variables to the preferred place of death. Women living with their husband or family tended to prefer to die at home compared with those living alone (59.7% vs. 40.5%, respectively;  $p=0.065$ ), but this tendency was not seen in men (Data not shown). No relationship between experience of death of someone living with them and preferred place of death was found in either sex.

The prevalence of family structure, self-rated health, number of neighborhood relationships, volunteer activities and preferred caregiver were significantly different between the home and non-home groups (Table 3). For men, factors that were significantly related to preferred place of death were preferred caregiver and the possibility of spending the end-of life period at home (if preferred). For women, factors that were significantly related to preferred place of death were self-rated health, number of neighborhood associations and participation in volunteer groups.

Table 4 shows the results of multiple logistic regression analysis. Analysis of all subjects revealed that good self-rated health (OR: 2.6, 95% CI: 1.2-5.7,  $p=0.013$ ), participation in volunteer activities (OR: 2.0, 95% CI: 1.0-3.8,  $p=0.038$ ) and preferred caregiver (spouse) (OR: 2.5, 95% CI: 1.3-4.8,  $p=0.007$ ) were associated with home as the preferred place of death. For men, factors that were significantly related to preference of home as the place of death were their spouse being their preferred caregiver (OR: 3.6, 95% CI: 1.2-10.6,  $p=0.018$ ) and the possibility of spending the end-of life period at home (if preferred) (OR: 3.5, 95% CI: 1.2-9.9,  $p=0.020$ ). For women, participation in volunteer groups was significantly related to preference of home as the place of death (OR: 3.2, 95% CI: 1.2-8.1,  $p=0.017$ ).

## Discussion

In the present study, we investigated the factors that influence the preferred place of death in Japanese community-dwelling older people. Both men and women preferred home as the place of death. In an analysis of all subjects, self-rated health, volunteer activities and preferred caregiver were associated with home as the preferred place of death. Analysis of each sex showed that significantly more men who preferred their spouse as their caregiver or acknowledged the possibility of spending the end-of life period at home and women who participated in volunteer groups gave home as the preferred place of death.

Good self-rated health was significantly associated with home as the preferred place of death in the analysis of all subjects in our study. To our knowledge, no reports have shown a direct association between self-rated health and preference of the place of death; however, some reports have focused on the association of self-rated health with mobility disabilities,<sup>25</sup> disabilities in basic activities of daily living,<sup>26</sup> quality of life<sup>27</sup> and disability-free life expectancy.<sup>28</sup> Thus, a person with good self-rated health probably also has good mobility function and quality of life, which may alleviate worry about admission to a medical institution or long-term care facility in the near future. One possibility is that a person with good health tends to prefer home as their place of death.

Conversely, a person with poor health may tend to prefer a medical institution or long-term care facility as their place of death. Health care personnel should be encouraged to discuss end-of-life care with elderly people while they are still in good health<sup>29</sup>.

According to the results of the analysis of all subjects, the spouse being the preferred caregiver was significantly linked to a preference of the subjects' own home as their place of death. In a Japan Cabinet Office survey on people aged  $\geq 20$  years, the most preferred caregiver among family members was the spouse (60.7%), and the prevalence was higher in men than women (men: 76.0%, women: 36.1%), which was consistent with our finding. A study in the United States surveying outpatients undergoing cancer treatment showed more men than women to prefer receiving care from their spouse.<sup>30</sup> Furthermore, in men, the spouse being the preferred caregiver was also significantly associated with a preference of home as the place of death. In general, men are often taken care of by their wives in regular daily life in terms of cooking, cleaning, shopping and when sick. This may be linked to the result that men tend to expect care from their spouse.

Participation in volunteer groups was significantly associated with the preference of home as the preferred place of death in the analysis of all subjects. People in a

community would provide support, including care to those who participated in volunteer activities. Alternatively, it is possible that people who participated in volunteer activities may feel more comfortable receiving support from people in the community. Our results suggested that structural SC (participation in volunteer groups) might be associated with choice of preferred place of death; however, this association was found in only women.

Women showed more extensive neighborhood relationships than men and many were involved in social activities in this study (data not shown). Similar results have been reported in other studies of SC.<sup>18, 22, 31</sup> This may partially explain the link found in our study between high structural SC and home as the preferred place of death in women.

Physical and mental support from family members is required to enable death at home. There is a strong likelihood that terminal cancer patients whose family members prefer them to spend their end-of-life period at home will do so, regardless of patients' own preferences.<sup>32</sup> Support from family members may require a good family relationship and mutual trust. In men, the possibility of spending the end-of life period at home (if preferred) was significantly related to home as the preferred place of death. It is possible that a high proportion of men in this study felt they could receive support from their family.

This study has several limitations. First, the number of subjects was relatively small. Second, the present study investigated older people living in Nagasaki Prefecture, Japan. As preference may vary according to region, it is possible that these results cannot be generalized to the entire older population of Japan. Third, this study only examined preference, and did not obtain information about the actual place of death. To elucidate these points, studies in other regions and longitudinal studies should also be conducted in the future.

In conclusion, factors influencing the selection of home as the preferred place of death among community-living elderly people were good self-rated health, participation in volunteer activities and spouse as the preferred caregiver. Therefore, it is necessary to consider individual preferences and public health strategies in order to enable elderly people to receive suitable and comfortable end-of-life care in their preferred location.

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**Table 1.** Characteristics of subjects (n = 178) and comparison between men and women.

		Total (n = 178)		
Variable		Men (n = 79)	Women (n = 99)	P-value <sup>a</sup>
Mean (SD)				
Age	Years	75.8 ( 5.8)	74.2 ( 6.3)	0.078
Length of residence in their current home	Years	34.0 (18.1)	32.7 (18.5)	0.641
Number (%)				
Family structure	Alone	8 (10.1)	37 (37.4)	<0.001
	Couple	58 (73.4)	40 (40.4)	
	Family	13 (16.5)	22 (22.2)	
Residence type	Own	75 (94.9)	92 (92.9)	0.757
	Rent	4 ( 5.1)	7 ( 7.1)	
Employed	Yes	10 (12.7)	18 (18.2)	0.408
	No	69 (87.3)	81 (81.8)	
Experienced the of death of someone living with them	Yes	31 (39.2)	58 (58.6)	0.016
	No	48 (60.8)	41 (41.4)	
Religion	Yes	71 (89.9)	91 (91.9)	0.793
	No	8 (10.1)	8 ( 8.1)	
Illness that requires regular hospital visits	Yes	56 (70.9)	72 (72.7)	0.867
	No	23 (29.1)	27 (27.3)	

<sup>a</sup> Chi-square test was used.

**Table 2.** Comparison the prevalence about preferred place of death between men and women

	Men (n = 79)	Women (n = 99)	P-value <sup>a</sup>
Their own home	54 (68.4)	52 (52.5)	
Medical institution	17 (21.5)	33 (33.3)	0.045
Long-term care facility	7 ( 8.9)	11 (11.1)	
Others	1 ( 1.3)	3 ( 3.0)	

Results are expressed as n (%).

<sup>a</sup> Chi-square test was used.

**Table 3.** Comparison of characteristic prevalence between the home and non-home

groups

		Total (n = 178)			Men (n = 79)			Women (n = 99)		
		Home (n = 106)	Non-home (n = 72)	P-value	Home (n = 54)	Non-home (n = 25)	P-value	Home (n = 52)	Non-home (n = 47)	P-value
Age	>74	49 (46.2)	35 (48.6)	0.762	24 (44.4)	15 (60.0)	0.232	25 (48.1)	20 (42.6)	0.687
Family structure	Alone	19 (17.9)	26 (36.1)	0.008	4 (7.4)	4 (16.0)	0.254	15 (28.8)	22 (46.8)	0.096
Length of residence in their home	>33 years	53 (50.0)	36 (50.0)	1.000	27 (50.0)	17 (68.0)	0.152	26 (50.0)	19 (40.4)	0.420
Residence type	Own	101 (95.3)	66 (91.7)	0.356	51 (94.4)	24 (96.0)	1.000	50 (96.2)	42 (89.4)	0.252
Employed	Yes	18 (17.0)	10 (13.9)	0.677	8 (14.8)	2 (8.0)	0.490	10 (19.2)	8 (17.0)	0.801
Experienced the death of someone living with them	Yes	51 (48.1)	38 (52.8)	0.647	22 (40.7)	9 (36.0)	0.806	29 (55.8)	29 (61.7)	0.683
Religion	Yes	97 (91.5)	65 (90.3)	0.795	50 (92.6)	21 (84.0)	0.254	47 (90.4)	44 (93.6)	0.718
Illness that requires regular hospital visits	Yes	71 (67.0)	57 (79.2)	0.090	36 (66.7)	20 (80.0)	0.292	35 (67.3)	37 (78.7)	0.260
Self-rated health	Good	89 (84.0)	50 (69.4)	0.027	44 (81.5)	18 (72.0)	0.384	45 (86.5)	32 (68.1)	0.032
Comfort level concerning local healthcare	Yes	78 (73.6)	50 (69.4)	0.611	44 (81.5)	20 (80.0)	1.000	34 (65.4)	30 (63.8)	1.000
Worry about medical costs	Yes	63 (59.4)	42 (58.3)	1.000	29 (53.7)	13 (52.0)	1.000	34 (65.4)	29 (61.7)	0.835
General trust of people in the community	Yes	101 (95.3)	64 (88.9)	0.143	51 (94.4)	24 (96.0)	1.000	50 (96.2)	40 (85.1)	0.081
Number of neighborhood relationships	Over 4	92 (86.8)	54 (75.0)	0.049	47 (87.0)	23 (92.0)	0.711	45 (86.5)	31 (66.0)	0.018
Volunteer activities	Yes	62 (58.5)	27 (37.5)	0.009	32 (59.3)	14 (56.0)	0.810	30 (57.7)	13 (27.7)	0.004
Preferred caregiver	Spouse	61 (57.5)	24 (33.3)	0.002	42	13 (52.0)	0.034	19	11 (23.4)	0.191
	Child	30 (28.3)	29 (40.3)		(77.8)	5 (20.0)		(36.5)	24 (51.1)	
	Son/Daughter-in-law	3 (2.8)	1 (1.4)		6 (11.1)	0		24	1 (2.1)	
	Sibling	1 (0.9)	3 (8.0)		1 (1.9)	2 (8.0)		(46.2)	1 (2.1)	
	Grandchild	0	0		1 (1.9)	0		2 (3.8)	0	
	Friend	0	1 (1.4)		0	0		0	1 (2.1)	
	Medical Staff	11 (10.4)	14 (19.4)		0	5 (20.0)		0	9 (19.1)	
					4 (7.4)			0		
Possibility of spending end-of-life period at home	Yes	65 (61.3)	40 (55.6)	0.535	40 (74.1)	12 (48.0)	0.040	7 (13.5) 25 (48.1)	28 (59.6)	0.314

**Table 4.** Odds ratio (OR) and 95% confidence interval (CI) for factors influencing the preferred place of death, as assessed using multiple logistic regression analysis

Total (n = 178)				
Variable		OR	95% CI	P-value
Self-rated health	Good / Poor	2.6	1.2 - 5.7	0.013
Volunteer activities	Yes / No	2.0	1.0 - 3.8	0.038
Preferred caregiver	Spouse / Other	2.5	1.3 – 4.8	0.007
Men (n = 79)				
Variable		OR	95% CI	P-value
Preferred caregiver	Spouse / Other	3.6	1.2-10.6	0.018
Possibility of spending end-of-life period at home	Yes / No	3.5	1.2- 9.9	0.020
Women (n=99)				
Variable		OR	95% CI	P-value
Family structure	Alone / Other	1.3	0.7- 2.5	0.370
Self-rated health	Good / Poor	2.4	0.8- 7.2	0.130
General trust of people in the community	Yes / No	2.4	0.4-14.2	0.342
Number of neighborhood relationships	>4 / 4≥	1.8	0.6- 5.7	0.341



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Volunteer activities	Yes / No	3.2	1.2- 8.1	0.017
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