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Factors associated with community residents' preference for living at home at the end of life: The Yamagata Cohort Survey

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Abstract: Japan's rapidly aging and high-mortality society necessitates a wider awareness and implementation of advance care planning. This Yamagata Cohort study investigated local residents' preferences for where they would like to spend their final days, and the underlying factors associated with those preferences with a self-administered questionnaire survey of local residents aged 40 years and over . Logistic regression analyses were used to assess those factors and, specifically, the choice of "Home" as the preferred place for end-of-life residence. Among the 10,119 responders, 61% chose their home as the most desirable place to spend their final days. The multiple logistic regression analysis showed that the independent factors associated with the choice of "Home" were: *male, older age, not living with someone who needs care, not discussing the end of life, currently happy, struggling to live on current income, not feeling anxious or depressed,* and current place of residence the same as their grandparents' birthplace. This suggested that reducing the burden of home care and addressing frequent emotional issues such as happiness and anxiety could increase the number of people choosing "Home". Open-ended comments indicated the importance of getting information and options, and discussing the choice of place for terminal care in light of individual backgrounds including having reservations about family. Support and systems are needed to understand what community residents consider important when deciding where to spend their final days, and to bridge the gap between their desired location and their actual end of life.

Keywords: final days, advanced care planning, terminal care, life choices

Introduction

As the demand for end-of-life care increases with the progression of an aging and high-mortality society in Japan, so does the need for advance care planning (ACP). ACP is a process in which the patient, their family, and their medical care team discuss in advance the medical care that the elderly patient desires and will receive in their final stage of life (I). Surveys of the general public and local residents have reported that one's own home is the most popular place to spend one's final days, with 36.6% to 60.0% choosing this option (2-5); however, only 17.2% of deaths actually occur at home (6). Furthermore, the desired place to receive terminal care varies widely depending on the presence or absence of terminal cancer, cardiac disease, or dementia, as well as the stage of the patient's illness (I).

Several studies have shown that the factors related to the individual attributes of those who prefer their own home as the place to receive end-of-life care and to spend their final days are *male*, *elderly*, and *living with a caregiver or children* (2-4); however, few detailed

surveys exist on this topic. Yamagata Prefecture has some of the highest aging and mortality rates in Japan; 33.8% of its population is 65 years or older, the mortality rate is 503.1 per 100,000, and the death rate from senility is 202.3 per 100,000 (the highest in Japan). Importantly, the death rate at home is only 14.4% (6), which is lower than the national average. The purpose of this study was to clarify the prevalence of local Yamagata residents who preferred their own home as the place in which they wished to receive terminal care, to explore the factors related to and the thoughts behind this preference, and to examine the issues involved in realizing people's wishes for their terminal care in a comprehensive community system.

Materials and Methods

Study participants and survey procedures

The Yamagata Cohort Study was supported by the 21st Century COE Program and the Global COE Program and was conducted in seven cities in Yamagata Prefecture

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from 2009 to 2015. Participants were local residents covered by the National Health Insurance system; most were engaged in agriculture, forestry, and fishery, were self-employed, part-time workers, retired workers, or unemployed. In the present study, health and lifestyle questionnaires were mailed from December 2021 to March 2022 to 17,527 of the 20,969 baseline participants (*i.e.*, those who responded to the original survey) who were known to be alive in December 2021. The questionnaires were returned by 12,216 respondents (response rate 69.7%), and analysis was conducted on the 10,119 who provided valid responses regarding the place in which they prefer to receive end-of-life care.

Survey items

The questionnaire comprised items that covered the following topics: sex, age, whether they discussed endof-life issues (Yes/No), whether they live with someone who needs care (Yes/No), whether they have a family doctor (Yes/No), whether they consult with family and friends (Yes/No), their current level of happiness (Happy/ Neutral/Unhappy), their living situation on their current income (Comfortable/Neutral/Suffering), Whether they feel forgetful (Yes/No), whether they feel anxious or depressed (Yes/No), whether their current residence and their grandparents' birthplace are the same (Same/ Not same), and what their preferences were for where they would like to spend the final days of their life by choosing "Home" or "Hospital/Nursing home/Other". Regarding where they would like to spend the final days of their life, "Hospital/Nursing home/Other" was defined as "Not Home", and comparisons were made between "Home" and "Not Home". In addition, an open-ended item was included in "Other".

Statistical analysis

A *t*-test and a chi-square test were conducted to compare continuous and categorical parameters between those who answered "Home" and "Not Home" as their preferred place to receive terminal care. Simple and multiple logistic regression analyses were conducted to identify factors independently associated with those whose preference was "Home". Open-ended items were qualitatively categorized and simply tabulated. A *p*-value of less than 0.05 was considered statistically significant. Statistical software JMP pro16 for Windows was used for all statistical analyses.

Ethical considerations

When the questionnaires were distributed, an overview of the study, including the voluntary nature of participation and the protection of personal information, was provided to the participants, and consent was obtained in writing. This study was conducted in accordance with the Declaration of Helsinki and was approved by the Ethics Committee of Yamagata University School of Medicine (2009–1222, 2022–193).

Results

Overview of participants and their preferences for where to receive their end-of-life care

The number of valid responses to the self-administered questionnaire was 10,119, of which 4,072 (40.2%) were male and 6,047 (59.7%) were female. The mean age was 71.9 ± 8.0 years; 1,649 (16.3%) were between 40 and 64 years old, 4,315 (42.6%) were 65–74 years old (*i.e.*, early elderly), and 4,155 (41.0%) were 75 years old or more (*i.e.*, late elderly).

The most common preference for where to spend one's final days was "Home" (6,184 participants, 61.1%). "Not Home" was 3,935 (38.8%), which included Hospitals (2,028, 19.2%), Nursing homes (1,818, 17.2%), and "Other" places (89, 0.84%). A total of 3,549 respondents (35.0%) reported that they discuss or have discussed end-of-life care with their families (Table 1).

We compared the characteristics of participants who chose "Home" as their desired place to spend their final days with "Not Home". Those who chose "Home" were more likely to be male (Home 45.1% vs. Not Home 32.5%), late elderly (Home 44.1% vs. Not Home 36.1%), had not discussed their end of life (Home 33.8% vs. Not Home 37.0%), were not living with someone who needed care (Home 7.8% vs. Not Home 9.8%), currently happy (Home 87.6% vs. Not Home 84.1%), not feeling anxious or depression (Home 26.7% vs. Not Home 31.8%), and living in a place of residence that was the same as their grandparents' birthplace (Home 46.4% vs. Not Home 39.6%).

Factors associated with the choice of "Home" as the preferred place in which to spend one's final days

We conducted simple and multiple logistic regression analyses on the factors associated with the answer, "Home", in response to the item, "place I want to spend my final days". In the simple logistic regression analysis, the associated factors were: male, late elderly, having end-of-life discussions, living with someone who needs care, being happy, not feeling anxious or depressed and the same current place of residence as the grandparents' birthplace (Table 2). In the multiple logistic regression analysis, the independently associated factors were: male (odds ratio [OR]: 1.59, 95% confidence interval [CI]: 1.45-1.74), late elderly (OR: 1.63, 95% CI: 1.43-1.85), not having end-of-life discussions (OR: 1.17, 95% CI: 1.07-1.28), not living with someone who needs care (OR: 1.18, 95% CI: 1.02-1.37), currently being happy (OR: 1.35, 95% CI: 1.18-1.55), having a difficult living situation on current income (OR: 1.16, 95% CI: 1.05-

Table 1. Participants' characteristics

Characteristics	Total 10,119 (100%)	Home 6,184 (61.1%)	Not Home 3,935 (38.8%)	<i>p</i> -value
Sex				
Male	4,072 (40.2%)	2,793 (45.1%)	1,279 (32.5%)	< 0.001
Female	6,047 (59.7%)	3,391 (54.8%)	2,656 (67.5%)	
Age group	-, (,	- / (/	, ()	
40–64 years old	1,649 (16.3%)	859 (13.8%)	790 (20.0%)	< 0.001
65–74 years old (Early elderly)	4,315 (42.6%)	2,592 (42.6%)	1,723 (43.7%)	
75 years old or more (Late elderly)	4,155 (41.0%)	2,733 (44.1%)	1,422 (36.1%)	
Having end-of-life discussions	, (,	,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,	, ()	
Yes	3,549 (35.0%)	2,090 (33.8%)	1,459 (37.0%)	< 0.001
Have a family doctor	-, ()	, ()	, (,	
Yes	9,164 (90.5%)	5,607 (90.6%)	3,557 (90.3%)	0.643
Living with someone who needs care	, , , , , ,	,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,	,,,,,,	
Yes	872 (8.6%)	486 (7.8%)	386 (9.8%)	< 0.001
Consultation with family or friends	,	, ,	, ,	
Yes	8,296 (83.6)	5,076 (83.7%)	3,220 (83.4%)	0.715
Current level of happiness	2, 2 2 (22 2)	,,,,,,	, (, ,	
Neutral	1,117 (11.2%)	626 (10.3%)	491 (12.7%)	< 0.001
Нарру	8,577 (86.2%)	5,325 (87.6%)	3,252 (84.1%)	
Unhappy	247 (2.4%)	125 (2.0%)	122 (3.1%)	
Living situation on current income	,	, ,	, ,	
Neutral	5,801 (58.9%)	3,541 (58.9%)	2,260 (59.0%)	0.045
Comfortable	1,046 (10.6%)	606 (10.0%)	440 (11.4%)	
Suffering	2,994 (30.4%)	1,865 (31.0%)	1,129 (29.4%)	
Forgetfulness	, , ,	, , ,	, , ,	
Yes	7,890 (78.8%)	4,799 (78.4%)	3,091 (79.4%)	0.218
Anxiety or depression	, , ,	, , ,	, , ,	
Yes	2,840 (28.7%)	1,615 (26.7%)	1,225 (31.8%)	< 0.001
Place of residence and grandparents' birthplace	, , ,	, , ,	, , ,	
Same	4,399 (43.8%)	2,848 (46.4%)	1,551 (39.6%)	< 0.001

Table 2. Factors associated with the desire to spend one's final days at Home

Factors	Simple OR (95% CI)	<i>p</i> -value	Multiple OR (95% CI)	<i>p</i> -value
Sex				
Male (vs. Female)	1.71 (1.57–1.86)	< 0.001	1.59 (1.45–1.74)	< 0.001
Age group				
40–64 years	1		1	
65–74 years old (Early elderly)	1.38 (1.23–1.55)	< 0.001	1.32 (1.17–1.74)	< 0.001
75 years old or more (Late elderly)	1.77 (1.57–1.98)	< 0.001	1.63 (1.43–1.85)	< 0.001
Having end-of-life discussions				
No (vs. Yes)	1.15 (1.06–1.25)	< 0.001	1.17 (1.07–1.28)	< 0.001
Have a family doctor	· · · · · · · · · · · · · · · · · · ·		, , , ,	
No (vs. Yes)	0.97 (0.84–1.11)	0.644	1.10 (0.96–1.28)	0.177
Living with someone who needs care				
No (vs. Yes)	1.28 (1.11–1.47)	< 0.001	1.18 (1.02–1.37)	0.030
Consultation with family or friends				
Yes (vs. No)	1.02 (0.92–1.14)	0.715	1.05 (0.93-1.18)	0.409
Current level of happiness				
Neutral	1		1	
Нарру	1.28 (1.13–1.46)	< 0.001	1.35 (1.18–1.55)	< 0.001
Unhappy	0.80 (0.61–1.06)	0.121	0.86 (0.65–1.16)	0.326
Living situation on current income				
Neutral	1		1	
Comfortable	0.88 (0.77-1.00)	0.059	0.90 (0.78-1.03)	0.141
Suffering	1.05 (0.96–1.15)	0.253	1.16 (1.05–1.28)	0.003
Forgetfulness				
No (vs. Yes)	1.06 (0.96–1.17)	0.218	1.06 (0.95-1.18)	0.280
Anxiety or depression				
No (vs. Yes)	1.28 (1.17-1.40)	< 0.001	1.15 (1.05–1.27)	0.004
Place of residence and grandparents' birthplace	,			
Same (vs. Not same)	1.32 (1.22–1.43)	< 0.001	1.23 (1.13–1.34)	< 0.001

1.28), not feeling anxious or depressed (OR: 1.15, 95% CI: 1.05–1.27), and the same current place of residence as the grandparents' birthplace (OR: 1.23, 95% CI: 1.13–1.34) (Table 2).

Subgroup analyses by sex and age

Since gender and age were strongly related to the choice of "Home" in the multivariate analysis of Table 2, we conducted subgroup analyses by gender and age considering the possibility that factors related to the choice of "Home" differ by gender and age. A total of 10,119 patients were included in the subgroup analysis. In the "sex" subgroup analysis, the associated factors for men were, in descending order of OR: being currently happy (OR: 1.56, 95% CI: 1.27–1.91), having the same current place of residence as the grandparents' birthplace (OR: 1.21, 95% CI: 1.05-1.39), and suffering in the current living conditions (OR: 1.17, 95% CI: 1.00-1.37). For women, the nine associated factors were, in descending order of OR: being late elderly (OR: 1.84, 95% CI: 1.57–2.15), being early elderly (OR: 1.39, 95% CI: 1.20–1.60), not living with someone who needs care (OR: 1.36, 95% CI: 1.13–1.64), having the same current place of residence as the grandparents' birthplace (OR: 1.24, 95% CI: 1.11-1.39), not having a family doctor (OR: 1.22, 95% CI: 1.02–1.46), being currently happy (OR: 1.21, 95% CI: 1.01-1.46), not having end-of-life discussions (OR: 1.21, 95% CI: 1.08-1.35), not feeling anxious or depressed (OR: 1.16, 95% CI: 1.03-1.31), and suffering in living situation on current income (OR: 1.16, 95% CI: 1.02-1.31). Thus, the factors associated with "Home" as the "place I want to spend my final days" differed by sex, with females having more facilitating factors than males (Supplemental Table S1, https:// www.globalhealthmedicine.com/site/supplementaldata. html?ID=73).

In the "age" subgroup analysis, the significantly associated factors in the 40–64-year-old group were, in descending order of OR: male (OR: 1.97, 95% CI:

1.55-2.50), being currently happy (OR: 1.40, 95% CI: 1.02–1.93), not having end-of-life discussions (OR: 1.32, 95% CI: 1.04–1.66), and suffering in living situation on current income (OR: 1.30, 95% CI: 1.04-1.63). In the 65-74-year-old (early elderly) group, the extracted five factors were: male (OR: 1.65, 95% CI: 1.44-1.90), being currently happy (OR: 1.31, 95% CI: 1.05-1.62), not having end-of-life discussions (OR: 1.21, 95% CI: 1.06–1.39), not feeling anxious or depressed (OR: 1.21, 95% CI: 1.04–1.41), and having the same current place of residence as the grandparents' birthplace (OR: 1.16, 95% CI: 1.03-1.33). In the 75 years and older (late elderly) age group, four associated factors were extracted: male (OR: 1.42, 95% CI: 1.24-1.63), being currently happy (OR: 1.39, 95% CI: 1.12-1.74), having the same current place of residence as the grandparents' birthplace (OR: 1.32, 95% CI: 1.15-1.52), and not feeling anxious or depressed (OR: 1.17, 95% CI: 1.00-1.37). The analysis clearly showed that the factors most commonly associated with "Home" as the "place I want to spend my final days" for all ages were male and being currently happy (Supplemental Table S2, https:// www.globalhealthmedicine.com/site/supplementaldata. html?ID=73).

Open-ended responses to the question, "Where do you want to spend your final days?"

Of those who answered "Other" to the question about where they would like to spend their final days, 306 provided qualitative responses in the open-ended items. The answers were categorized by descriptive similarities, as follows: "Don't know/can't decide/thinking about it", "Specific place (e.g., fee-based senior citizen home, hospice, or child's home) ", "Depends on the physical condition and situation at the time", "Does not think about it or does not want to think about it", "Abides by the family's wishes or a place that does not disturb the family and surroundings", and "No preference/anywhere is fine" (Figure 1). Actual examples of "Don't know/can't

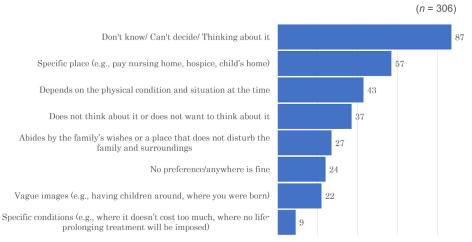


Figure 1. Open-ended response to the question, "Where do you want to spend your final days?"

decide/thinking about it" statements were: "I don't know because I have never thought about it", and "My spouse is dead and I am an elderly person living alone so I have no one to consult". A further example of "Depends on the physical condition and situation at the time" statement was, "Hospital if I am sick, nursing home if I have dementia, home if I am well". Another example of "Abides by the family's wishes or a place that does not disturb the family and surroundings" was, "Anywhere that will not inconvenience my family". A further example of "Specific place" was, "A nursing home that is adequate for my income".

Discussion

Factors associated with "Home" as the "place where I want to spend my final days"

In this study, several factors associated with "Home" as the preferred place to receive end-of-life care were consistent with previous studies (2,3): male, not living with a person in need of care, early elderly, and late elderly. Importantly, new associated factors were also found: not having end-of-life discussions, being currently happy, difficulty living on one's current income, not feeling anxious or depressed, and the current place of residence being the same as the grandparents' birthplace. Furthermore, subgroup analyses showed that the associated factors differed by sex and age: females had more multiple associated factors, and all age groups were associated with the common factors.

Not having end-of-life discussions

In this study, 61.1% of the respondents who preferred "Home" as the place in which to receive end-of-life care reported not discussing where they would spend their final days. Inagaki et al., by contrast, reported no difference between holding end-of-life discussions and the preferred place for end-of-life care (2). One possible reason for this is that a low percentage of the participants in the present study had discussed end-of-life care, and it is possible that they did not have a concrete image of what their end-of-life care would be or of the place where they would spend their final days. However, the open-ended answers suggest that perhaps these participants wished to stay at home but were hesitant to tell their families about their wishes because they did not want to bother their families or were simply unsure, and as a result, they did not discuss end-of-life care with their families.

Being happy and not feeling anxious or depressed
No previous study has examined the association between
being happy and not feeling anxious or depressed, and
the preferred place for spending one's final days. Our
results suggest that for a person who is currently happy
at home and has no anxiety, the idea of wanting to spend

their final days at home is a natural extension of their present life. It is also possible, however, that participants are optimistic about the possibility of spending their final days at home as an extension of their current life because they are unable to visualize information and options such as illness and nursing care. Further investigation is needed to determine the relationship between sudden physical deterioration owing to aging and the availability of information about situations requiring nursing care.

Difficulty living on current income

Sugimoto *et al.* suggest that economic level can lead to decision-making that is contrary to the will of the individual and their family members (7); those in lower economic brackets have fewer opportunities and less capacity to care for their elderly than those in higher economic brackets, and thus may initiate home care for unavoidable reasons and are less likely to express a preference for spending their final days at home. Furthermore, Noguchi reports that the elderly with dementia may not be able to choose the place of treatment for their terminal care owing to the limitations of family caregiving and economic hierarchy that cannot afford the cost of institutionalization (8).

As the present super-aging society emerges in Japan, people's economic situations and their family's lack of caregiving capacity may prevent them from choosing nursing homes or long-term care facilities, and they may be forced to choose their own home. We believe that social support policies and the provision of easily accessible information are necessary to enable people to choose the medical treatment they desire at the end of their lives.

Current place of residence is the same as the grandparents' birthplace

Although this study did not investigate the rate of cohabitation, 43.8% of respondents were born and continue to live — in the same place as their grandparents, which may indicate that they are familiar with and attached to the community and their home. In the Nippon Foundation's survey report (4), respondents gave reasons for choosing their current home, such as "I feel safe and the surroundings are familiar" and "I can be myself until the end of my life". The survey also found that for local residents, those who continue to live in the place where they were born and raised are more likely to want to stay at home. Furthermore, the participants in the present study were agricultural, forestry, fisheries or self-employed workers, this may have contributed to their desire to stay in the familiar surroundings of their hometowns or homes until the end of their lives.

What local residents consider important when thinking about the place to receive their end-of-life care

Although 95.8% of participants in this study indicated a

specific preference for where they wanted to spend their final days, only 35.0% had actually discussed end-of-life care with their families. In addition to the main category, "Don't know/can't decide/thinking about it", the themes that were extracted from the open-ended responses indicate a wide variety among local residents in their considerations of where to spend their final days and receive terminal care, which depends on their individual circumstances and associated choices (e.g., "follow family's wishes, a place that will not bother family or surroundings" and "depends on physical condition and circumstances at the time"). This outcome may be an indication of the difficulty that Japanese people tend to experience in being both reserved and assertive toward their families and others.

The category, "follow the family's wishes and do not want to inconvenience the family and surroundings" has also been mentioned in previous surveys as a factor that is taken into consideration when thinking about terminal care (1,9). The results of a Nippon Foundation survey (4), however, show a discrepancy between parents' and children's end-of-life medical care and recuperation preferences and their thoughts about those choices: parents do not want to "burden the family" at the end of their life, but children may not know this reality and want their parents "to receive aggressive medical treatment" and "to live as long as possible". For this reason, we believe it is important for families to discuss not only the physical location of the place where the person wants to spend their final days, but also the thoughts behind the person's wishes.

Many participants also indicated that their choice of location for spending their final days and receiving terminal care "depend[s] on the physical condition and circumstances at the time of death". The Japanese Ministry of Health, Labour and Welfare promotes the establishment of a comprehensive regional support and service delivery system to enable the elderly to continue to live their lives in their familiar neighborhoods for as long as possible. The objective is to preserve people's dignity, support independent living, and provide palliative care and end-of-life care at home regardless of disease or physical condition, as well as the enhancement of services to reduce the burden of care on families. However, available resources and maintenance conditions vary from region to region (10) and the options are likely to be narrowed depending on factors such as economic level (7) and the presence or absence of dementia (8). Public health approaches to end-of-life care have the potential to enhance the integration of services and provide a comprehensive approach that engages the assets of local communities (11). Therefore, when discussing places for end-oflife care, it is important for local residents to have knowledge and information about the actual medical and nursing care options available in their area for terminal physical and mental health conditions.

Towards a community where people can choose "Home" as the place where they spend their final days

Surveys of the preferences of the general public and terminally ill people report a growing consensus that, with sufficient support, most people would prefer to receive end of life care at home (12). Table 2 shows that among the factors related to not choosing to stay at home, the items that can be improved include: avoiding having a person in need of care at home, increasing the number of people who feel happy in their current situation and increasing the number of people who are not anxious/unhappy. Each of these is found with frequency in having a person in need of care at home (8.6% of all respondents), not feeling happy in the current situation (Unhappy 2.4%, Normal 11.2%) and being anxious/depression (28.7%). In particular, addressing the more frequent, mental health issues such as happiness and anxiety could significantly increase the number of people choosing "Home" as the place where they spend their final days.

Conversely, this is might also true for those who choose "Home" as a place to spend their final days, who are satisfied with their current living environment, have less anxiety and fear about the end of life and image of death, and have a more positive view of death. Maintaining health and well-being may lead to better end of life care (13), and creating a community where more people choose "Home" may help to create a society where residents are healthy in mind and body, benefit from a comprehensive community system and live a happier life now.

Strengths and limitations of this study

The strengths of this study include the large sample size (the largest among past surveys in Japan) and the large geographical area from which responses were obtained within the prefecture. These factors facilitate an understanding of the preferences and thoughts of a wide range of local residents regarding places in which to receive end-of-life care. Several limitations should be noted. First, there may have been selection bias. The participants in this study regularly receive community health checkups, have a high level of health awareness, and are currently in good health; therefore, they may not have information on or specific images of end-oflife medical care or be aware of the options available to them for places of recuperation. Second, this survey was conducted only once. Participants' opinions may change depending on their physical condition and surrounding circumstances.

Conclusion

This study identified factors associated with community residents' desire to spend their final days at home. When considering where community residents should spend their final days, it is necessary to understand their personal characteristics and what is important to them, and to provide support and systems that can bridge the gap between their desired location and their actual end of life.

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