

# BMJ Open Factors associated with preferred place of death among older adults: a qualitative interview study in Tama City, Tokyo, Japan

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## ABSTRACT

**Objectives** To analyse the cognitive processes involved in the decision-making of older adults who are not in the end-of-life stage regarding the selection of a preferred place of death.

**Design** A qualitative cross-sectional study based on semistructured in-depth interviews. The interview scripts were sectioned by context, then summarised, conceptualised and categorised. Post-categorisation, the relationships between the conceptual factors were examined.

**Setting** Tama City, Tokyo, Japan, from November 2015 to March 2016.

**Participants** 20 long-term care users and their families or care providers were interviewed about their preferred places of death and the factors behind their decisions.

**Results** Three categories based on the preferred place of end-of-life care and death were extracted from the interview transcripts: (A) discouraging the decision of a preferred place of death, (B) enhancing the desire for home death and (C) enhancing the desire for a hospital/long-term care facility death. Category A consists of concerns about the caregiver's health, anxiety about solitary death, and constraints of and concerns about the household budget. Both categories B and C consist of subcategories of reinforcing and inhibiting factors of whether to desire a home death or a hospital/long-term care facility death. If their previous experiences with care at home, a hospital or a care facility were positive, they preferred the death in the same setting. If those experiences were negative, they tend to avoid the death in the same setting.

**Conclusions** One's mindset and decision regarding a preferred place of death include the consideration of economic factors, concerns for caregivers, and experiences of care at home or in a hospital/long-term care facility. Furthermore, health professionals need to be aware of the ambivalence of senior citizens to support their end-of-life decisions.

## INTRODUCTION

Advance care planning (ACP) is defined as 'enabling individuals with decision-making capacity to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ As a strength of this study, the participants, who were not at the end of life, discussed how to decide preferred place of death.
- ⇒ A limitation is that participants may not have previously thought about their preferred place of death, so their responses might be without contemplation.
- ⇒ The findings of this study largely depend on the culture and social system of the target population, which limits the generalisability beyond the study population.

healthcare providers, and to record and review these preferences if appropriate.' It includes physical, psychological, social and spiritual aspects. Individuals are also recommended to designate a proxy decision-maker to document their preferences and revise the documentation periodically.<sup>1</sup> However, the global penetration rate of ACP remains low. While an estimated 33% of the adult population aged 18 years and over in the USA have undertaken ACP, the percentage is less than 1% in Japan and Australia and 7%–8% in the Netherlands and the UK.<sup>2–7</sup> In Japan, approximately half of the population wants to die in their own home.<sup>8</sup> However, this desire does not become a reality for most, as ultimately only 12% die at home.<sup>9</sup> Therefore, promoting ACP is vital for bridging this gap in the future. An examination of how ACP has reached its current standing in the USA may be an important key to identifying how to increase its usage in Japan.

ACP is widely considered an essential step toward achieving optimal end-of-life care, consistent with the preferences of dying patients and their families.<sup>10</sup> Furthermore, it has been shown to reduce wasteful and costly end-of-life treatment, prioritise palliative care and improve patients' quality of life at the end-of-life stage.<sup>11</sup> Studies have found

that when patients' end-of-life choices are respected, the satisfaction of the bereaved is higher, and cases of depression, post-traumatic stress disorder and anxiety disorders are reduced.<sup>12</sup> A reduction was observed in the percentage of patients with anxiety and depression after 14 weeks of ACP implementation.<sup>13</sup> In a systematic review, ACP was also associated with better consistency between representatives' and patients' wishes and actual care received, increased number of patients dying in their preferred location, increased ACP-related documentation, increased discussions around ACP, and decreased unwanted life support treatments, resource utilisation, and hospitalisation rates.<sup>14</sup>

However, several studies have reported several barriers to ACP implementation. Barriers influencing healthcare professionals include insufficient time, inability to electronically transfer the ACP documentation across care settings, decreased interaction with patients nearing the end-of-life stage owing to transfer of care, and patients' difficulty in comprehending the limitations and complications of treatment options.<sup>15</sup> Barriers influencing patients included a low ACP implementation rate among older adults with low levels of education, income, assets and home ownership.<sup>16</sup> Additional barriers to ACP implementation include being too young for ACP, emotional avoidance of the topic, assuming that the doctor should be responsible for implementing ACP, fear of a negative impact on the patient–physician relationship, lack of time during doctor's appointments to discuss ACP, concerns about the impact of ACP on family dynamics, perception of ACP as a low-priority task and lack of knowledge about ACP.<sup>17</sup>

The question regarding when to start ACP can be a barrier for both patients and healthcare professionals. Some studies state that the sooner the better,<sup>18</sup> while others state that it is ideal to start ACP with regular doctor visits between the ages of 50 and 65 years.<sup>19</sup> It has been suggested that starting ACP too early could be a disadvantage for patients.<sup>20</sup> Thus, a major difficulty is that the best time to begin ACP is unclear. Considering the differences in illness trajectory, patients with malignant tumours, for instance, are already diagnosed at the time of discharge, and therefore, it is relatively easy for them to start ACP. In contrast, for patients experiencing senility, organ failure, dementia or frailty, the question of when to start ACP is difficult, and they are less likely to start ACP on their own, adding to the complexity.<sup>21 22</sup>

Rietjens *et al* concluded that ACP enables individuals to define goals and preferences for future medical treatment and care, discuss these goals and preferences with family and healthcare providers, and record and review the preferences if appropriate.<sup>1</sup> Cohen *et al* surveyed the preferred place of death of patients with cancer and patients without cancer across 4 continents and 14 countries.<sup>23</sup> Death at home ranged from 12% (South Korea) to 57% (Mexico), and hospital death ranged from 26% (the Netherlands and New Zealand) to 87% (South Korea). In all countries surveyed, most individuals who

died in long-term care facilities were patients without cancer. Patients with cancer are more likely to die in palliative care facilities than patients without cancer, and this difference was greater in England, Wales and Australia. All countries had a higher rate of home death among married people, while Europe had a higher rate of home death among people with a higher level of education and patients with cancer in urban areas. This difference was only partly explained by age, gender, cancer type, number of hospitals, facilities and doctors; therefore, other factors that significantly contribute to this difference need to be identified and examined. Future cross-national qualitative research can help better understand the reasons for the same.<sup>23</sup>

The number of older adults who are sent to emergency hospitals and hospitals with palliative care wards is increasing. In Japan, the death rates in medical facilities (including hospitals and clinics) and nursing care facilities were 72.9% and 11.9%, respectively, in 2019. However, the number of home-visit nursing stations that provide medical support for patients living at home has also increased in recent years. Irrespective of regional differences, there is a strong correlation between the rate of home-visit nursing and the number of home deaths.<sup>24</sup> Additionally, the number of medical facilities that provide end-of-life care services at home is gradually increasing. Nevertheless, the total accounts for only approximately 5% of all hospitals and clinics. Almost 60% of people consider it impossible to spend their final days at home for reasons such as burden on their family or anxiety related to coping in the event of a sudden change in their condition. Thus, the number of paid nursing homes that effectively resolve these concerns has been on the rise, and so have the deaths in nursing care facilities.<sup>25</sup>

Although many Japanese people wish to die at home, hospital and nursing care facility deaths are common, even with increasing support systems for people who choose to die at home. This may be because of several factors. A complex cognitive process is thought to occur between choosing one's preferred place of death as part of ACP and deciding on one's actual place of death. An in-depth understanding of this psychological process is essential to examine the factors that make the adoption of ACP difficult. In this study, older adults who have maintained or decreased their activities of daily living (ADLs), but are not terminally ill, are interviewed regarding where they want to spend their final days to examine the cognitive process behind choosing a preferred place of death.

## METHODS

### Study design

This qualitative cross-sectional study was based on semi-structured in-depth interviews conducted between November 2015 and March 2016 in Tama City, Tokyo, Japan.

## Participants

The inclusion criteria for participants were Long-term Care Insurance (LTCI) users aged 65 years and over in Tama City, Tokyo, who had the cognitive capacity to comprehend and discuss the study topic. LTCI is a mandatory programme for the people over the age of 40 years in Japan to provide support to senior citizens in need of long-term nursing care.<sup>26</sup> Sampling was conducted by the chief administrative officer of the Tama City Medical Association. He assigned local care managers (certified professional to manage LTCI service provision) to select LTCI users who met the above criteria. Only LTCI users have been selected because they are aware of their functional weaknesses and have regular consultations with their care managers. Couple participation was allowed if they liked, then we counted them as two participants in one household. If participants asked other members, a son/a daughter and/or a care manager, to join the interview, we did not regard them as a participant but the participant's advocate.

Recruitment was purposefully conducted across four timings with approximately five participants in each session. We started the interview after a certain number of participants were selected from care managers. Analysis was repeatedly performed after each timing, and new participants were added to our study until theoretical saturation was reached.

Of those who consented to participate in the interview, two participants dropped out. One participant was due to admission to a nursing care facility after a fire at home and the other requested to cancel the interview in advance without disclosing any reason.

## Interview administration method

Each interview was scheduled for approximately 1 hour and included a preliminary explanation of the study and the completion of an informed consent form. The interview location was generally the participant's home to ensure a comfortable setting. For interviews with participants living in nursing care facilities, a shared space was used; however, confidentiality was ensured in all cases.

A qualitative approach using one-on-one in-depth interviews for data collection was implemented. The interviews comprised a list of questions, including the location where the participant would prefer to receive end-of-life care and background factors influencing their choice (see online supplemental appendix). The interviews were conducted by five trained interviewers who had no prior relationships with the participants.

## Interview analysis

The interviews were recorded using a digital voice recorder. All audio recordings were transcribed and divided among the five members of the research team to create a summary of the content.

First, after several rounds of in-depth analysis, data selection and summarisation were conducted. Second, the members of the research team regularly discussed

data interpretation and conceptualisation during the data analysis process. Theoretical saturation was confirmed based on the absence of new concepts or categories in the fourth group of participants. Last, while comparing the concepts with those of other researchers, categorisation and creation of a conceptual diagram were finalised.

We used the Modified Grounded Theory Approach,<sup>27</sup> developed from the Grounded Theory Approach proposed by Glaser and Strauss in 1967.<sup>28</sup> The interviews were conducted by four members (TT, YO, AM and FI) under the supervision of one member (HO) with recording by a digital voice recorder. All audio recordings were transcribed and divided among the interviewers for a content summary. We regularly discussed data interpretation and conceptualisation during the data analysis process. We focused on the relevant parts of the data and created concrete examples, concept names and definitions using analysis worksheets. As for the degree of perfection of the generated concept, we confirmed the data not only from the confirmation of similar cases but also from the relation of comparison with the opposite polar cases. We examined the relationship among concepts, generated categories, summarised the results, documented the outline and created a result diagram. We evaluated if any concept or category was added and confirmed theoretical saturation. Finally, we discussed factors associated with preferred place of death among older adults.

## Patient and public involvement

There was no participant involvement in the participant recruitment, interview and data analysis of the study.

## RESULTS

The study participants consisted of 16 interviewed households comprising 20 participants (table 1). The male participants were aged 70–100 years, with an average age of 86 years. The female participants were aged 70–90 years, with an average age of 81 years. Care levels were determined by the municipal panel based on insurance application status: 2 participants had not applied for LTCI services, 8 were certified as requiring support and 10 as requiring long-term care. Four participants lived alone, 13 with spouses and 8 with their children. The interview duration ranged from 20 to 61 min, with an average of 47 min.

## Qualitative analysis

The following three categories, based on the preferred place of end-of-life care and death (hereinafter referred to as the preferred place of death), were extracted from the interview transcripts: (A) discouraging the decision about a preferred place of death, (B) enhancing the desire for home death and (C) enhancing the desire for a hospital/long-term care facility death.

Category A, discouraging the decision of a preferred place of death, included the following concerns: (A1)

**Table 1** Background of participants

ID*	Age	Sex	Cohabitants†	Thoughts on preferred place of death
#1	80s	F	Husband and a son	Has no preference
#2	100s	M	None	Prefers death at his daughter's house
#3	80s	F	A son, her husband and a grandchild	Has never thought about it
#4	80s	M	None	Prefers hospital death
#5	70s	M	Wife	Prefers home death but has financial concerns
#6	80s	M	Wife	Prefers hospital death
#7	90s	M	None	Prefers death at the same long-term care facility where his wife stays
#8	80s	F	Husband	Prefers hospital death
#9	70s	M	None	Prefers home death
#10	80s	M	Couple only	Prefers home death
#11	70s	F		Prefers hospital death
#12	70s	M	Couple with a daughter, her husband and a grandchild	Prefers hospital death
#13	70s	F		Prefers hospital death
#14	90s	M	Couple with a daughter	Prefers home death
#15	90s	F		Prefers hospital death
#16	80s	F	Husband and a son	Preferred home death, but prefers hospital death after discussion
#17	80s	M	Couple only	Has never thought about it
#18	70s	F		Has never thought about it
#19	90s	M	A daughter	Maybe home, but unsure
#20	70s	F	A son	Prefers facility or hospital death

\*Numbers following the # symbol correspond to the ID numbers.

†Merged lines mean the same household. Their interviews were conducted in one session.

concerns about the caregiver's health, (A2) anxiety about solitary death and (A3) constraint of and concerns about the household budget.

#### A1. Concerns about the caregiver's health

We might have unexpected events because we are human being. If I was hospitalised in such situations, my husband couldn't live anymore, because he has never done anything alone... (#8)

Even if he does not want to go to the hospital or enter a facility, I know he may have to go to such a place eventually in case I am sick or I cannot do anything. If I get sick, I will not be able to do for him anymore, so we will have to enter a facility. Even though I know that time will come, I get very nervous when I think about it; I cannot help it, and I do not know how it will end. (#11)

#### A2. Anxiety about solitary death

I wish everyone could be there in my final moments, but what if no one stays with me? (#14)

#### A3. Constraint of and concerns about household budget

I worry about the financial concerns to enter a nursing home. I haven't searched it very much, but I think

special elderly nursing homes cost less and their price is affordable. However, those facilities are so popular that many people are waiting in line. If we think of the facility my friend's mother lives, it looks gorgeous but we cannot afford it. (#11)

It is ridiculous to spend our whole life doing business and struggling hard to pay taxes and insurance. We cannot take it easy as we get older. The burdens become increasingly heavier. That is why we cannot get sick without economic stability. (#16)

Category B, enhancing the desire for home death, was classified into two subcategories: (B1) reinforcing factors for home death and (B2) inhibiting factors for hospital/long-term care facility death. B1 was further divided into four concepts: (B1.1) loving and supportive relationships with spouse, (B1.2) loving and supportive parent-child relationship, (B1.3) positive home medical care experience and (B1.4) satisfaction with community life. B2 was further divided into three concepts: (B2.1) concerns about care for dementia during hospitalisation, (B2.2) negative experience during hospitalisation and (B2.3) concerns about the cost of hospital/long-term care facilities.

## B1. Reinforcing factors for a home death

### B1.1. *Loving and supportive relationship with spouse*

He does not like new places anyway. That is why I thought I would take care of him at home if I could. (#8)

### B1.2. *Loving and supportive parent–child relationship*

My father wants to live at home, so as one of his family, I want to live up to his wishes. And, if he were to become bedridden for years, we would take care of him the whole time. (#14)

### B1.3. *Positive home medical care experience*

It is really helpful because medical care is provided more or less 24/7. Without it, we would not be able to do this at home anymore. (#19)

### B1.4. *Satisfaction with community life*

The environment around our house is very good and it's enjoyable to get along with our neighbours. Everyone says hello to each other. The chairman of the senior people's gathering in our town is very kind and takes good care of us. (#14)

## B2. Inhibiting factors for a hospital/long-term care facility death

### B2.1. *Concerns about care for dementia during hospitalisation*

I was told by the hospital staff that my father (cognitively impaired) intended to go home and tried to pull out the tubes. That is why the staff warned us, 'It's difficult for us to take care of him.' and 'Please go to another place'. (#19)

### B2.2. *Negative experience during hospitalisation*

I have really learned a lot from the hospital. There are many different people in the area. What I did not understand was that of dementia. I could not understand it from the appearance. When I saw a patient with dementia in the ward, I did not understand what the patient thought and wanted to do. I am not able to imagine that I will die like a dementia patient in the ward. (#2)

### B2.3. *Concerns about the costs of hospital/long-term care facilities*

If we have a certain amount of money, we can go to the hospital easily. But if we do not have enough money, even if we suffer from a disease, we have to be patient at home. (#5)

Category C, enhancing the desire for hospital/long-term care facility death, was classified into two subcategories: (C1) inhibiting factors for home death and (C2) reinforcing factors for hospital/long-term care facility death. C1 was further divided into two concerns: (C1.1) concerns about family members' burden of nursing care and (C1.2) concerns about future frailty. C2 was further divided into four categories: (C2.1) sense of security given by a hospital, (C2.2) positive experience during hospitalisation, (C2.3) positive experience at a long-term

care facility and (C2.4) possibility of a lifelong stay at a long-term care facility.

## C1. Inhibiting factors for home death

### C1.1. *Concerns about family members' burden of nursing care*

I could not do something like having my son take care of me, and if he did try to take care of me, he'd probably be the one to fall down and die instead. This is because I think about it from many different perspectives. (#20)

If I am at home, it is only my wife and me, so she would end up keeping very busy. The hospital has many nurses and attending physicians. (#6)

### C1.2. *Concerns about future frailty*

If there was a home-visit nursing care system, I think it would be fine to stay at home. However, there are many things, such as taking care of the private parts. Since my body would get quite weak before I die, at home would be a little... It would be hard without anyone to look after me. (#4)

## C2. Reinforcing factors for a hospital/long-term care facility death

### C2.1. *Sense of security given by a hospital*

The feeling that I would like to take my mom to an inpatient facility has gotten stronger and stronger. (#13)

### C2.2. *Positive experience during hospitalisation*

I have been admitted to XX hospital and XX University Hospital. I was happy to be able to relax and read many books, probably because my life at home was busy (laughs). (#8)

### C2.3. *Positive experience at a long-term care facility*

In that way, I'm very grateful to the staff of XX nursing home. I do not hesitate to say anything that is on my mind there, whatever it may be. (#7)

### C2.4. *Possibility of lifelong stay at a long-term care facility*

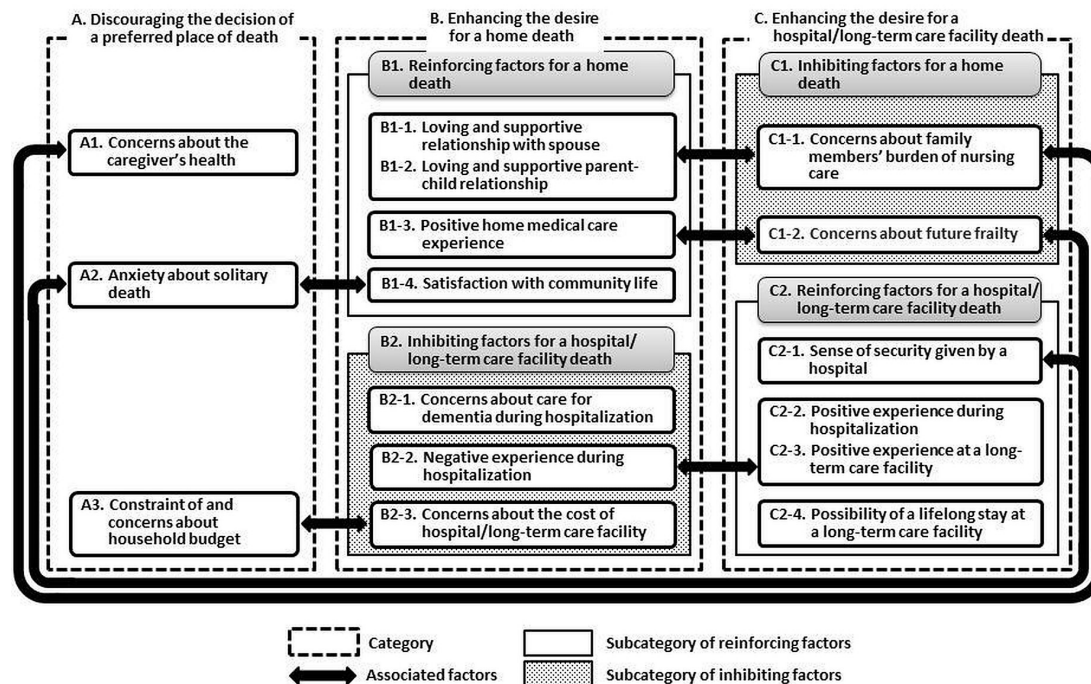
For about two years, she was asking me to come every day, but in the third year she really took a liking to XX nursing home, and now she does not talk about going back home. (#7)

## DISCUSSION

Results from the interviews with older adults suggested three categories of psychological processes for deciding the preferred place for death. Older adults seem to be ambivalent while deciding between home death and hospital/facility death, and if the uncertainty is high, they might withhold decision-making. The associations between these factors for hypothesis formation are shown in [figure 1](#).

The first factor in category A was anxiety about caregivers' health (A1). Even if a patient wants to die at home, concerns about the caregiver's health might make

## Psychological Factors When Deciding the Preferred Place of Death



**Figure 1** The relationship between being unable to decide on a place of death, increasing the desire for home death and increasing the desire for hospital/facility death when older adults think about their preferred place of death.

it difficult to express the desire for a home death. Aged individuals who need full-time home care have no choice but to depend on the caregiver; therefore, if the caregiver becomes sick, they can no longer stay at home. In Japan, the proportion of home deaths in older adult households comprising a couple (eg, husband and wife) is lower than that in households with a single individual. It is assumed that the rate of home death decreases for older married couples because caring for a loved one at the end-of-life stage may be difficult without additional help.<sup>29</sup>

In Japan, 49.1% of married couples over the age of 65 years live on their own, while 23.4% of couples aged 75 years and above live independently. The rates of spousal care were even higher, with 89.8% of primary caregivers over the age of 65 years and 57.1% over the age of 75 years.<sup>30</sup> Although the introduction of LTCI services has reduced the burden of caregiving, some services are essential to ADLs, such as eating, toileting and bathing. Professional care cannot be provided for household chores, such as cooking, cleaning and laundry unless a senior individual lives alone. This is because the LTCI system was created for situations in which there is already a healthy caregiver present; therefore, it is not suited for vulnerable caregivers. For older adults to have their desire of home death fulfilled with the support of their ageing spouses, the current LTCI service system requires drastic reforms.<sup>31</sup>

The second factor was anxiety about solitary deaths (A2). In figure 1, this concept is associated with (B1.4) satisfaction with community life, (C1.1) concerns about future frailty and (C2.1) the sense of security given by a

hospital. The percentage of older adults ( $\geq 60$  years old) who did not prefer solitary death was 17.3%, but this rate increased to 45.4% for those living alone.<sup>32</sup> In the past, Japan was a village-centred society, and the concepts of 'self-reliance' and its complementary concept of 'mutual reliance' greatly impacted people's lives. Gradually, Japanese society shifted from 'mutual reliance' to 'self-reliance,' with the development of 'public assistance' leading to a society of weakening relationships. However, people who have fewer opportunities to engage with community members are more motivated to participate in community activities.<sup>33</sup> B1.4 implies that seniors' sense of security comes from living in harmony and mutual reliance with the local community, thereby reducing anxiety and building resistance against solitary death. Moriki *et al* showed that people who keep community engagement tend to have a discussion regarding place of death preferences.<sup>34</sup> Good relationships with the community will reduce factors that make it difficult to think of desired places of death, such as anxiety about solitary deaths. These findings highlight the importance of promoting activities that revitalise local communities.

The final factor was anxiety regarding economic inconvenience (A3). Anxiety about financial issues is a lingering concern for both the home and hospital/care facility. Economic factors were cited as a cause of concern for 30.6% of those who desired home death and 11.5% for those who desired hospital death.<sup>35</sup> The present study also identified (B2.3) concerns about the cost of hospital/long-term care facilities further demonstrate that financial capacity is a major consideration when

determining the place of death. In the USA, low-income individuals are unable to receive ongoing care at home and eventually move to hospice care.<sup>36</sup> Kinjo *et al* showed that medical costs for hospitalisation were 16.7% higher than for home care at the end-of-life stage.<sup>37</sup> Anxiety about medical care costs may explain why older adults in Japan choose to die at home. When conducting ACP, it is important to provide cost information on home care and hospital/long-term care facilities and to make financial plans, including current savings and the projected amount that will be needed during the patient's end-of-life period.

The first two factors of subcategory (B1) reinforcing factors for home death were (B1.1) loving and supportive relationship with one's spouse and (B1.2) loving and supportive parent-child relationships, both associated with (C1.1) concerns about family members' burden of nursing care. A survey by the Ministry of Health, Labour, and Welfare found that 88.3% of common people selected a hospital or a long-term care facility as the preferred place of death. Such individuals were asked additional questions about why they did not select their home, and 64.7% chose (if they stayed at home in the end-of-life stage) that they may impose a nursing care burden on family caregivers.<sup>35</sup> Hattori *et al* also argued that the strongest factor affecting end-of-life care is family, stating that people prefer dying at home surrounded by their family to dying alone in the hospital. However, they also feel conflicted, which may be inconvenient for their families.<sup>38</sup> Most people in Japan like to spend as much time as possible at home. However, when they consider the possibility of nursing care at old age, they do not want to impose the burden of nursing care on their families and feel that their families should have some say in the matter. Some also felt they did not have a say regarding their own deaths.

Although deciding on one's preferred place of death, where one will spend the last days of life, seems to be one of the most important decisions in ACP, the findings of the present study suggest that the decision-making process varies by culture. Hasegawa *et al*<sup>39</sup> conducted a comparative survey on end-of-life care in Japan and other countries. In the case of terminal cancer, in all other countries, it is common and ideal for the patient to make the final decision regarding ACP; however, in Japan, the decision-maker is often the patient's son. In addition, in Japan, health professionals tend to mention 'family care burden' and 'financial burden' to the family members during the decision-making process for the care, management and treatment of the patient. This reflects the attitude of health professionals who put more weight on considering the care burdens on family members.<sup>39</sup> Thus, in Japan, when conducting ACP, the patient's options are decided by gathering the opinions of not only the patient but also the family. A similar tendency has been reported in other Asian countries.<sup>40</sup>

(B1.3) Positive home medical care experience reinforces the choice of home death; however, the

experience of caring for a family member suffering from severe diseases such as cancer may reinforce the choice of hospital death due to (C2.1) the sense of security provided by the hospital. The Japanese government promotes doctors' and nurses' home visits to increase home medical care, yet anxiety about the availability of emergency care, a 24-hour communication system, and the absence of home-visit doctors and nurses persist among patients.<sup>25</sup> Therefore, there is an urgent need to eliminate this anxiety related to end-of-life care through the seamless provision of home medical care including increasing the number of visiting doctors and a 24/7 reception system of available doctors/nurses.

(C2.2) Positive experience during hospitalisation or (C2.3) at a long-term care facility reinforces the desire for hospital/facility death, while negative experiences of B2.1, B2.2 and B2.3 lead to a desire for a home death. When conducting ACP, inquiries about not only the patient's history of hospitalisation/stay at a care facility but also specifically about their experience, whether positive or negative, will help make better decisions.

In summary, if older adults have concerns regarding category A factors, discouraging the decision of a preferred place of death, they are more likely to procrastinate or withhold decisions. Unless factors in category A interfere, he/she may compare the death at home and a hospital/long-term care facility. Even if he/she has a covert desire for home death, concerns about family members' burden of nursing care or positive feelings/experiences during hospitalisation/stay at a care facility may allow him/her to express a desire for a hospital/care facility death. To fulfil the desire for home death, not only the factors in category B but also family members' cooperation and appropriate consideration for the senior member would be required.

When conducting ACP, many people may not have experienced the inconveniences of hospitalisation or stay at a care facility, pain at the end-of-life stage or cognitive impairment; therefore, it can be difficult for them to make a decision. Recognising factors related to the decision-making process regarding the preferred place of death (figure 1) may facilitate the better use of ACP.

In the future, we would like to focus further on how to facilitate the decision-making process regarding whether the preferred place of death should be home, a long-term care facility or a hospital, and the reasons for the same. Furthermore, we plan to delve into the mindset of families at the time of a family member's end-of-life stage, focusing on relationships and generational continuity as background factors.

### Study limitations and challenges

This study used a purposeful sampling of elderly people and their families who were capable of giving an interview with care manager. Some family members have not had discussions regarding ACP before, and we slowly and gradually asked about this issue in our study. The depth of the interview depends on the study participants,



interviewers and their interaction. Hattori *et al* interviewed older adults about end of life and found that some older adults changed their views on their end-of-life plan during the course of the interview. They had little interest in the interview, no personal desires and left the decision-making to others.<sup>38</sup> If they may not have previously thought about their preferred place of death, so their responses might be without contemplation. Additionally, participants of this study were senior adults in Tama City, Tokyo. Therefore, the findings of this study largely depend on the culture and social system of the target population, which limits the generalisability beyond the study population.

## CONCLUSION

This study suggests that decisions about one's preferred place of death involve a complex combination of economic factors, concern for family caregivers, feelings of anxiety at home, and experiences with medical treatment and long-term care. Regarding the preference for home death, the present research indicates that decisions cannot be made if the patient is unable to discuss it with family members and care providers. Future studies should demonstrate the relationship between these findings.

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