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LETTER TO THE EDITOR

## Feeding tubes in the terminal frail elderly

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Dear editor,

It is distressing to decide how to treat the frail elderly in the terminal stage.<sup>1</sup> The increased number of frail elderly in Japan forces us to confront the serious decision of not treating the frail elderly with feeding tubes in the terminal stage. In Japan, because of strong family emotions, religion, social customs and public opinion, it is very difficult to refuse feeding tubes when patients are suffering from dysphagia.<sup>2</sup> Japanese physicians agree to the use of feeding tubes out of fear that they will be accused of refusing to tube feed patients for economic and financial reasons.

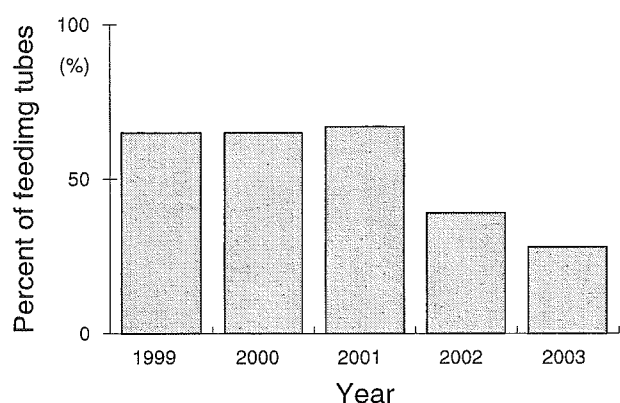
Kosaka *et al.* asked the families caring for tube-fed patients about how and why they accept tube feeding,<sup>3</sup> whether to recommend tube feeding to families if their relative suffers a terminal illness, and whether they would accept tube feeding themselves if they were suffering from a terminal illness. They found that 66% of families caring for patients with tube feeding permitted tube feeding because there was no other way for the patient to survive. However, about 90% of families caring for patients with tube feeding rejected the idea of being tube fed themselves in a similar situation. The same response was also given by families caring for patients eating by themselves and outpatients.

According to previous studies,<sup>3</sup> we asked families who had a frail elderly relative in the terminal stage of disease whether the families chose a feeding tube or not for patients with dysphagia. Eligible frail elderly were terminal patients who required tube feeding because they had difficulty maintaining adequate nutrition orally and their cognitive function was extremely poor and not improving. Patients were in long term care for several reasons, including physical disabilities, mostly due to cerebral strokes, and by the request of the patients' families. These patients continued to deteriorate to the point where they did not have any conscious awareness although they occasionally opened their eyes and made noises. However, the eye movements and the noises they made were not discernibly purposeful. With the

consent of team staff, including nurses and care givers, we took informed consent by explaining previous data,<sup>3</sup> which showed that about 90% of families caring for patients in the terminal stage refused the option of feeding tubes. We also indicated to them the prognoses in both the event that they were fed and if they were not. Drip infusion from peripheral veins was accepted in cases without feeding tubes. Approximately 1000 mL of drip infusion containing electrolytes and vitamins was performed under careful observation for edema, urine volume and so on. Without any previous instructions, full explanations of the consequences of both alternatives on the terminally ill patients were given and the families chose one method. Informed consent was started from August 2002 until July 2004. We compared the decisions regarding the use of the feeding tubes in the terminally ill from before taking informed consent (August 1999 to July 2002) with those made afterwards (August 2002 to July 2004).

We examined 102 patients in the terminal stage with dysphagia (mean age  $\pm$  SD  $82 \pm 8$  years): 58 women ( $82 \pm 8$  years of age) and 44 men ( $80 \pm 8$  years of age) who were bedridden at Hikarigaoka Sperman Hospital, a geriatric long-term care facility in Sendai City, Japan. The number of patients annually from 1999 to 2003 were 23, 20, 15, 18 and 26 patients, respectively. Before July 2002, the proportion of patients with feeding tubes varied from 65 to 67%, but after August 2002 they decreased to 39–28% (Fig. 1). Fifty-two patients ( $80 \pm 7$  years of age: 29 women and 23 men) selected feeding tubes and the other 50 patients ( $84 \pm 8$  years of age; 29 women and 21 men) selected peripheral drip infusion. There were no systematic differences in age, cognitive impairments or basic diseases between patients with and without tube feeding.

Infections, including pneumonia, were observed in 72% of the patients with feeding tubes and 25% of the patients with peripheral drip infusion. Nine patients with feeding tubes and one patient with peripheral drip infusion survived to the end of December 2004. The average survival period of patients who died with feed-



**Figure 1** Proportion of feeding tubes for frail elderly in the terminal stage decreased by half after taking informed consent by explaining that about 90% of the families had denied feeding tubes since August 2002.

ing tubes was  $447 \pm 65$  days (mean  $\pm$  SD) and that of patients who died with peripheral drip infusion was  $65 \pm 7$  days (mean  $\pm$  SD). The average medical cost of dead patients with feeding tubes was  $618 \times 10^3 \pm 121 \times 10^3$  yen per month and that of dead patients with peripheral drip infusion was  $525 \times 10^3$  yen  $\pm 182 \times 10^3$  per month. Total medical costs of dead patients with feeding tubes was  $9214 \times 10^3 \pm 1804 \times 10^3$  yen per person (mean  $\pm$  SD) and that of dead patients with peripheral drip infusion was  $1156 \times 10^3 \pm 401 \times 10^3$  yen per person (mean  $\pm$  SD).

The difference in acceptance of tube feeding between the reality of being tube fed and the thought of rejecting tube feeding, may be due to Japanese morals. Japanese families find it hard to accept death even in patients who have decreased cognition, no will and who are bed bound. However, rejecting tube feeding in about 90% of the families caring for terminal patients might decrease tube feeding by half.

About 100 000 patients in geriatric hospitals all over Japan die per year, which represents about 10% of all deaths in Japan.<sup>2</sup> Medical fees for the patients who died were spent largely in the terminal stage.<sup>4</sup> If the proportion of feeding tubes was reduced by half, as shown in the present study, medical costs in the terminal stage would decrease tremendously, because the medical cost of feeding tubes was about eight times higher than that of peripheral drip infusion. Life elongation with treatment depending on the family's desire and the public health system, which covers almost all medical costs without limitation, might be one of the reasons for continuing terminal medical care.<sup>5</sup> On the other hand, feeding tubes may be used as means of saving costs because

the staff time required to feed patients by hand is expensive.<sup>6</sup> An attempt to reduce the length of hospital stay may promote decisions to place feeding tubes in an acute care setting. In the present study we took informed consent from families caring for patients in the terminal stage.

Finucane *et al.* reviewed the evidence to identify data about whether tube feeding in patients with advanced dementia can prevent aspiration pneumonia,<sup>7</sup> prolong survival, reduce the risk of pressure sores or infections, improve function or provide palliation. They found no data to suggest that tube feeding improves any of these clinically important outcomes and found some data to suggest that it does not. Further, risk was substantial. They suggested that the widespread practice of tube feeding should be carefully reconsidered, and for severely demented patients the practice should be discouraged on clinical grounds. In contrast, in Japan, decisions on how to treat the terminal elderly are different from those of Western countries, because of differences in terms of philosophy, religion, family emotions, social customs and public opinion. These are partly derived from Confucianism in which the virtue of filial piety is strongly stressed. It may not be justified to cease feeding tubes in terms of benefits and risks as it is in Western countries, but it also may be wrong to prolong survival in most cases in the terminal stage of dementia. A middle ground for decisions on feeding tubes in Western and oriental countries might be suitably settled in future.

The present study is an attempt to construct a medical consensus for life-extending care in terminal older patients.

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# A Qualitative Exploration of Elderly Patients' Preferences for End-of-Life Care

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## Abstract

**Objectives** The objectives of this investigation were to understand, at a broader and deeper level, the wishes of the elderly in Japan concerning their end-of-life care, and to clarify their end-of-life wishes in order that care providers might better understand them.

**Design** Descriptive study drawing on interview data comprising responses to open and closed-ended questions.

**Setting** Patients attending a university hospital and a university-affiliated geriatric clinic were interviewed in a private room near their own rooms or the clinic they attended.

**Participants** Seventeen elderly patients who were hospitalized in a university hospital and 13 elderly patients who received medical services from a university-affiliated outpatient facility.

**Measurements** An interview was designed to address three major domains: 1) wishes for care at the end of life, 2) patient preferences for information about their illness, and 3) the meaning of death.

**Results** Wishes for care at the end-of-life were influenced by various factors, namely; family, health condition, personal experience, relationship with physician, and concept of life and death. Wishes expressed in relation to these factors often varied during the interview however, the wish to “die in comfort” remained consistent.

**Conclusion** Palliative care providers should understand that elderly patients' wishes for end-of-life care may be dependent upon their own ability to make decisions, that their wishes may change during the decision-making process, and that family considerations are a strong influence on decisions, however the desire to die in comfort remains highly stable.

**Key words** End-of-life care, Patient preference, Elderly patient, Qualitative study

## The Background and Purpose

World population projections for the 21st century show that the transition to an aging society is occurring at a rapid pace both in developed and developing countries.<sup>1</sup> Japan is one of the most prominent examples of a nation with a rapidly aging society since the rate of aged death con-

tinues to rise rapidly.<sup>2</sup> This situation has made end-of-life care for elderly patients an important social and medical issue in Japan and other nations around the world.

Most clinicians and researchers agree that improvement of the patients' quality of life is an important goal in palliative care. One important factor in achieving this goal is “to meet the wishes of the patients.”<sup>3</sup> Thus, it is important to know

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**Table 1 Characteristics of elderly inpatients**

Participants	Gender	Age	Recorded time (min)	Living with his/her family
1	Female	73	60	No
2	Female	74	60	Yes
3	Female	67	50	No
4	Male	76	60	Yes
5	Female	84	50	Yes
6	Male	76	50	Yes
7	Female	80	55	Yes
8	Male	78	45	Yes
9	Female	81	60	Yes
10	Male	81	50	No
11	Female	77	50	Yes
12	Male	73	45	Yes
13	Female	73	50	No
14	Female	78	60	Yes
15	Female	71	55	No
16	Female	81	45	Yes
17	Male	75	45	Yes

**Table 2 Characteristics of elderly outpatients**

Participants	Gender	Age	Recorded time (min)	Living with his/her family
1	Female	88	50	Yes
2	Female	87	50	Yes
3	Female	82	50	No
4	Female	78	55	Yes
5	Female	88	60	Yes
6	Male	88	70	Yes
7	Female	82	55	Yes
8	Female	79	45	No
9	Female	78	50	No
10	Female	75	65	Yes
11	Female	86	65	Yes
12	Female	85	55	Yes
13	Female	83	45	No

what kind of end-of-life care, elderly people want, yet in Japan, little research has been conducted on this subject. There has been previous work in Japan especially on end-of-life decision-

making with regard to cancer disclosure and euthanasia<sup>4-12</sup> though these have not primarily focused on elderly patients' preference for end-of-life care. The research that has been done to

date has largely employed quantitative survey methods.<sup>13,14</sup> These studies have revealed that the most elderly Japanese do not wish for life-sustaining treatments, but desire palliative care if they become terminally ill; approximately 70 percent wish to die in their own homes; and a large number of patients wish to be informed about the nature of their illness, no matter how old they may be. However, in these surveys, the areas investigated were limited to items included in closed-ended questions.

The objectives of this investigation were to understand, at a broader and deeper level, the wishes of the elderly in Japan concerning their end-of-life care, and to clarify these wishes in order to help care providers understand them. A qualitative design was determined most appropriate for this study in order to elucidate the background and context of elderly patients' wishes, and to understand those wishes through the voices of participants themselves rather than solely in terms pre-defined by a research instrument.<sup>21</sup>

## Methods

This investigation employed a qualitative design that generated rich, textual data from personal interviews. This design allowed the research team to investigate the processes and conditions that affect elderly patients at the end of their lives, and to understand their wishes about these factors during this important time. To maximize variation among the sample along the spectrum of acute to chronic health status, we recruited participants from both one inpatient setting and one outpatient setting.

The subjects consisted of 17 elderly patients, age 65 and over, who were hospitalized in a university hospital and 13 elderly patients who received medical services from a university-affiliated outpatient facility between February and July 2000. Only subjects who were not in an acute, life-threatening condition and who could talk for approximately one hour were eligible.

Patients with dementia were excluded from participation. Subjects ranged from 67 to 88 years of age (mean age: 79.2 years); 23 were female and 7 were male. Table 1 and 2 include information regarding age, gender, recorded time, and family status for inpatients and outpatients.

The interviews with the hospitalized patients were conducted by Y.M., and outpatient by A.H.

An interview guide was designed to address three major domains: 1) wishes for care at the end-of-life, 2) preferences for information about the illness, and 3) the meaning of death.

Corresponding questions on the semi-structured interview guide included:

- 1) What wishes do you have for your own end-of-life care? Where would you like to be when you die? Whom would you like to have at your bedside at the time of your death?
- 2) To what degree would you like to have a detailed explanation concerning the selection of treatment? To what extent would you like to be part of the decision-making for your treatment?
- 3) What does death mean to you?

In this paper, we have focused only on the results from the first and third domains.

## Participant consent

Procedures for recruiting and obtaining consent differed between the hospitalized and outpatient participants. To reduce stress for the hospitalized participants, a written copy of the interview questions was given to the subjects at the time they consented to being involved. In the process five patients declined to participate further. Interviews were then conducted one to three weeks later. Hospitalized participants received interviews in a private conference room near their own rooms. Each interview lasted about an hour. Since it was not feasible to circulate the questionnaires prior to in the outpatient environment, outpatient participants were interviewed at the point their consent was gained. Thus outpatient participants were not able to consider the questions in advance nor did they have the time to reassess their desire to participate. However we did consult nurses in advance about suitable patients for this inquiry and after receiving consent from the outpatients that were recommended, we again considered whether or not the interview questions would be acceptable to each individual. Finally, all consenting outpatients were interviewed. We also used a private conference room to interview outpatient subjects. Each interview lasted between 40 and 90 minutes. Interviews were recorded on audiotapes and transcribed verbatim.

## Data analysis

We analyzed this qualitative data using the

**Table 3 Contents of wishes for the end-of-life**

Category of the end-of-life wish	Content of the wish
<b>Wishes for the end-of-life circumstance</b>	
Place of death	Home Hospital Hospice Anywhere
Who is wanted at bedside	Family members One who will listen to one's tale No one; Want to be alone
Treatment and decision-making	Refuse life-sustaining treatment Receive adequate pain and symptom management Entrust others with decision making
State of death	Die easily and without suffering Avoid dependency Avoid being bedridden
<b>Factors influencing wishes for end-of-life care</b>	Family Relationship with physician Health condition Personal experience Concept of life and death
<b>Transformation and consistency of wishes for end-of-life care</b>	
<b>Die in comfort</b>	

process of immersion/crystallization.<sup>22,23</sup> The analysis for this report focused on patients' wishes for end-of-life care and the circumstances prior to their death. We independently identified preliminary categories and emphasized the use of *in vivo* codes. The coders discussed and resolved any coding discrepancies. The codes and associated passages were then entered into a qualitative analysis database.

Steps were taken to maintain the trustworthiness of the qualitative research.<sup>24</sup> These were then iteratively compared in order to refine the categories that ultimately were used to encode the transcripts. Analytical memos from both analysts were used to refine the categories and extract themes. By iteratively refining the codes and categories, the analysts were careful to ground the emergent themes in the data, and interviewing was completed at the point of saturation.

Theoretical saturation was achieved by continuing to interview additional participants until no new themes emerged.<sup>25</sup> No new themes

emerged from the interviews with the last four individuals recruited. Theoretical verification of the study results was assessed by asking four individuals who had participated in the study to respond to the results.<sup>24</sup> All participants responded that the results accurately represented their and their acquaintances' attitudes.

The methodology of the study was approved by the Ethics Committee of School of Medicine, Nagoya University.

## Results

Analysis of the text data yielded four major themes (Table 3): 1) wishes for end-of-life circumstances, 2) factors influencing participants' wishes for end-of-life care, 3) the transformation of wishes for end-of-life care, and 4) the desire to die in comfort. Together, these results guided the development of a conceptual model, the amoeba model of elderly patients' wishes for care at the end of life (Fig. 1).

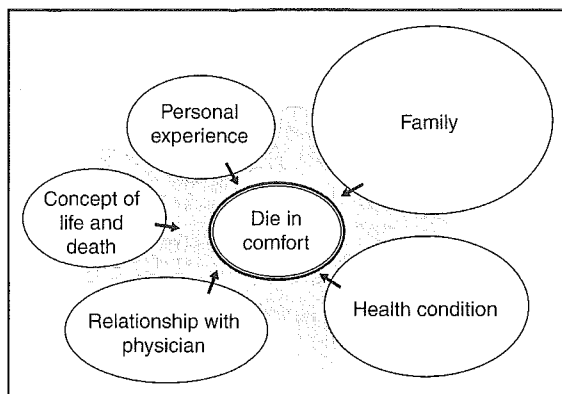


Fig. 1 The amoeba model of elderly patients' wishes for care at the end of life

### Wishes for end-of-life circumstances

Wishes for end-of-life circumstances emerged as a theme from the interviews. From among those relevant statements, the wishes were further categorized into two subcategories (see Table 3). The first subcategory involved those wishes concerning the circumstances around the time of death, such as place of death, whom they wanted at their deathbeds, and avoiding extensive life-prolonging treatment. These factors were elucidated by interview questions that addressed the first domain, discussed above. The second subcategory, which related to the state of death, emerged from the data through statements like, "I wish to die easily, without suffering," or "I hope to not be bedridden for a long period of time."

### Factors influencing wishes for end-of-life care

The reasons behind participants' wishes for their end-of-life care were examined in detail, and comments related to factors influencing their wishes were extracted and categorized as: family, relationship with physician, health condition, personal experience, and concept of life and death.

**Family:** The family factor clearly influenced the place of death and whom they would like to have at their bedsides. Relevant data included statements like: "reservation and consideration toward the family," "expectation," "resignation," and "family background." This factor, in particular, influenced many subjects in their preferences for place of death.

Almost all participants mentioned family members when answering the question, "Whom

would you like to have at your death bed?" The consistency of this response further implicated family as the reason why they originally had wanted to die in their own homes. In contrast, those living alone wished to die in a hospital for fear their conditions might worsen if they were alone at home:

*Look, can't you see that dying in a hospital with someone around would be better than dying alone without anyone knowing?*

(78-year-old female outpatient)

While family was a prominent theme, participants also struggled with how to balance their desire to have family close with the burden end-of-life care would be on their loved ones. This struggle was revealed through statements such as this one made by a 78-year-old hospitalized female:

*I see others being nursed by their families and see how strenuous it is for the younger people to take care of the elderly. It takes time and labor, and it also puts a lot of psychological burden on them. I love my daughter and son, and so that's why I don't want to burden them, if possible.*

**Relationship with physician:** Many of the participants mentioned having faith in and reliance upon their doctors, and this trusting relationship influenced their wishes for their end-of-life care. Their trust was typically directed toward a specific medical institution or doctor. When the hospital was the place of death, they entrusted the appropriate selection of treatment to the doctors.

*No matter how much I think about it, there's nothing I can do but to trust the doctor here. I don't know anything (about medicine), so I leave everything to my doctor. If I leave it up to my doctor, I'll have nothing to worry about.* (84-year-old hospitalized female)

**Health condition:** A number of participants wished to be placed in a nursing facility when the time came, assuming their physical functions would deteriorate and they would require nursing care in the future. Again, the family burden factor played a role in their responses. There were also some who wished to be hospitalized for treatment if they were in pain.

*Right now, I could be on my own, but I wonder whether my daughter would be able to care for me. So, I think I should be in a place like this so I can be taken care of.*

(88-year-old female outpatient)

*When the time comes when I can't be on my*



*own, I guess I'll have to go into the hospital to be taken care of. If I go into a hospital, they'll give me an injection for treatment and take care of me. That would be better, I guess.*

(88-year-old female outpatient)

**Personal experience:** Several of the participants, when speaking of how they wanted to die, gave examples of their experience caring for a family member during that person's end-of-life period. They particularly expressed their desire to die in the same manner as family members or acquaintances who had died within a short period and with little suffering. In contrast, those who had experienced the death of a family member who had been bedridden for a long time without being able to communicate with the family expressed their desire to avoid such a situation. Participants' personal experience clearly influenced their wishes for their end-of-life period.

*Both Grandma and Grandpa died of heart attacks while they were walking on the street. I heard my oldest brother died all of a sudden while watching TV. My other older brother died within two or three minutes from choking on mochi (a sticky rice cake). I want to die like them!*

(86-year-old female outpatient)

*My sister's husband passed away suddenly the other day. He hadn't been ill for long. It was what we consider a good way to die. Everyone envied him because he "died so well." I would like to die like that, too.*

(83-year-old female outpatient)

**Concept of life and death:** Several participants expressed their attitude toward the end of their life by saying they did not care but preferred, instead, to leave the decision up to others. There were also those who had — more or less — abandoned hope, while some had never given any thought to their death. Underlying the latter attitudes seemed to be a concept of life and death, which appeared in statements like: "What will be will be in the end." "Our fate is already set, so there is no sense in thinking about it." In addition, several subjects stated their opinions concerning their life and death philosophically as epitomized by the following statements:

*I have lived long enough so I will leave the rest to others. I don't care if I die at home or in a hospital, Do I want someone at my bedside? I don't need anyone. Man is born alone and die alone. No one could do anything*

*even if there was someone at my deathbed. Wherever I die, that will be the end of me. What's important is how I lived at the prime of my life. (67-year-old hospitalized male) I can't say that I want this or that done for me, because I have left that up to the ones who are nursing me, so I really don't have any wishes. What can I do about it? Even if I said how I wanted to be cared for, there's no guarantee that they'd listen to me. Well, I think whatever happens will be my fate, so I'll have to go along with it.*

(74-year-old hospitalized male)

Such concepts of life and death expressed the subjects' interest in or apathy toward their own death, the latter being expressed through giving themselves up to others and/or to what they perceived as their fate.

#### **Transformation and consistency of wishes for end-of-life care**

As stated above, wishes concerning end-of-life care are influenced by the respective background of participants, and consideration of family, health condition, relationship with the physician, personal experience of their family members' deaths, or concept of life and death. However, when discussing their care preferences, study participants often seemed to talk themselves from an initial desire into a different conclusion. For example, some participants initially indicated their wish to die in their homes, however, after considering the nursing burden this would place on the family, later changed their minds and concluded that, instead, they would prefer to die in a hospital. Which factors influenced the wishes and the degree of the influence depended on the individual.

*If it is possible, I want to die at home with my children around me . . . .*

Then later:

*. . . Even if that doesn't work out, I don't mind because people die anywhere.*

(73-year-old hospitalized female)

*If possible, I want to die at home . . . .*

Then later:

*. . . I'll go along with my doctor's decision, whatever he decides is best for me, so I won't insist on it dying at home.*

(78-year-old hospitalized female)

By contrast, others were interviewed offered consistent responses. Such participants consis-

tently gave either firm wishes concerning their end-of-life environment, from the beginning right the way through to the end of the interview, or did not express any strong wishes. Right from the start of the interview, these patients showed little interest and held no personal hopes for their end-of-life circumstances. Phrases such as “I don’t care” or “I’ll leave it up to others” seemed to indicate they would want their desire to match the intentions of their families and medical practitioners.

Although some patients were consistent either in expressing apathy, or in their expression of a firm wish, the majority of subjects wishes appeared to change during the course of the interview.

### The desire to die in comfort

Though there was a tendency for some of the participants to change their mind showing how their train of thought developed and their wishes for their end-of-life care and circumstances changed, most participants expressed a strong wish to “die in comfort.” While they would entrust end-of-life decisions, such as the place of death or the selection of the treatment, and some also had an “I do not mind either way” attitude, the desire to “die easily, without suffering” was the most prevalent underlying wish, and one which never changed.

*I don't want to be bedridden. I tell everyone that I want to die in a situation where everyone realizes that I am dead. I want to be moving around until the very last minute. That way, I won't have to suffer for a long time before I die. But I have to die some day. I've passed my 80th year, so my time is just around the corner, but I'm not afraid to go. I just don't want to die in agony. I want to just drop dead.* (88-year-old female outpatient)

Moreover, as expressed by the female outpatient above, most patients wished not to be bedridden for a long time and to die within a short period. Therefore, the desire not to be bedridden for a long period of time is included in the wish for a comfortable death.

There were a few who emphasized the merits of euthanasia. For example, one participant had this to say:

*I wish people would let me die in my sleep. You know, there was a doctor in Kyoto who was charged for giving a potassium chloride*

*injection, but I think that is one possible way to die. Don't you think it would be good to go to the other world in sleep, without any pain or suffering?*

(67-year-old male inpatient)

### The amoeba model of elderly patients' wishes for care at the end of life

The amoeba model of elderly patients' wishes for care at the end of life is depicted in Figure 1. This conceptual model illustrates a “nucleus wish” for comfortable death surrounded by often-transforming and changing end-of-life wishes. This wish to die in comfort forms the nucleus of the amorphous and ever-changing amoeba. The double-lined border in the middle of the gray amoeba in the model represents the permanence and significance of subjects core desire to die in comfort. While some patients were initially able to articulate their wishes and these remained relatively consistent, it was more commonly seen among the subjects that they changed their wishes. This model illustrates the relationship between the changeable wishes of the subjects, and the factors that change their wishes. The irregularly shaped gray cytoplasm represents patients' changeable wishes concerning end-of-life circumstances, and the various-sized vacuoles surrounding the amoeba-shaped area identify the factors influencing those wishes.

Hence, the wishes for end-of-life care by the subjects are like the vacuoles in an amoeba. While semi-morphous, the size and shape of patients' wishes gradually change and evolve, somewhat like vacuoles inside the cytoplasm of an amoeba. Like vacuoles, these wishes are ultimately incorporated into the nucleus and become an integrated part of the core without changing the fundamental premise of the desire to die in comfort.

### Discussion

This qualitative investigation has used the voices of participants to explore issues surrounding the wishes of elderly Japanese patients for their end-of-life care. We have gathered their comments from the interviews and extracted various factors influencing patients' wishes. Although most of their expressed wishes often changed over the course of their respective interviews, the desire to die in comfort remained stable throughout.

These findings are highly consistent with several other qualitative studies that also examined end-of-life issues.<sup>15-20</sup> Steinhauser et al. revealed that "to be free from pain" is the most important factor that people considered regarding end-of-life. "To die without pain" may be the final wish for many people.<sup>16</sup> In an anthropological investigation comparing end-of-life care in the United States and Japan, Long also found as a central theme the importance of a peaceful death.<sup>4</sup>

One theme of this analysis that is important for health care providers is the progression of wishes concerning the end-of-life period. In research reported by the International Longevity Center Japan, researchers distributed a survey to examine the self-determination process of elderly patients. Rather than insisting on their own wishes, some of the elderly patients trusted and left decisions to family members and doctors.<sup>26</sup> Finally, there were many subjects with "fluid opinions", hoping to make their own decisions if circumstances allowed. Triangulation of the data from the current study with results from these quantitative studies seem to support a strong case that evolution of wishes may be a consistent pattern among the elderly in Japan. This should be considered when discussing end-of-life care choices with elderly patients.

The transformation of patient wishes described in the amoeba model of elderly patients' wishes for care at the end of life as a process seems unlikely to be particular to the Japanese. In North America, self-determination for medical care, particularly self-determination leading to an advanced directive concerning end-of-life treatment, is considered to be one of the fundamental rights held by human beings.

In contrast to North American thinking, Japanese people's sense of ego—according to one view—has not yet been established.<sup>27</sup> Rather, from this perspective, it could be argued that human beings are part of nature, and so should leave their destiny to nature and fate, and that as with other forms of death, human death is to be accepted as a natural part of the life course.<sup>28</sup> Such cultural conditioning of elderly Japanese people may be influencing their wishes for the end of their lives. This can, possibly explain—at least to some extent—the nature of the changes and transformations of our interview subjects' wishes.

An investigation conducted in Canada<sup>29</sup> reported that there are two types of patients: "activists," who desire to make their own decisions, and "delegators," who leave the decision up to nature, fate and God. The study pointed out that the delegators tended to be a less-educated, lower-income group. Many Japanese people, on the other hand, seem to hold a cultural concept of life and death similar to the delegators in the Kelner study, regardless of education or income.<sup>28</sup>

During this investigation, the family, health condition, trust in the physician, experience, and concept of life and death were all confirmed as factors influencing the wishes of the elderly. Of these factors, consideration of family members was the strongest influence, with most of the subjects feeling burdened by the thought of imposing the provision of nursing care on their family. Subjects expressed the feeling that, in reality, they could not expect too much home care, and would relinquish their original wish to die in their own homes. Previous authors have similarly illustrated the importance of family influence on Japanese decision-making concerning end-of-life context.<sup>7,8,30,31</sup>

The Family factors also typically arise among qualitative investigations concerning wishes for the end of life in Western countries. Moreover, consideration of the burden of asking family to provide nursing care is common among subjects in both cultures.<sup>16,32,33,34</sup> A culture in which the decision-making by the family is placed at a higher priority than the wishes of the patients, themselves, is not unique to the Japanese group, but is also reported in other ethnic groups.<sup>35,36</sup> In the United States there are also many elderly patients who express a desire to respect the decision of the family rather than insisting on their own directive concerning their end-of-life treatment should they lose their decision-making ability.<sup>37</sup> This evidence suggests that consideration of the family over individual wishes for end-of-life care may not be culturally distinct, but may not necessarily be an omnipresent, phenomenon either.

These data illustrate that patients worry about becoming ill and bedridden and that such health conditions influence their wishes for end-of-life care. Long has demonstrated that conflict between self-reliance and being a burden is an important factor in the Japanese context vis-à-vis attitudes toward euthanasia or suicide.<sup>11</sup>

This investigation found that some subjects have considerable confidence and reliance in their doctors and toward the medical institutions from which they receive outpatient treatment. This, in turn, tended to influence their wishes concerning their end of life, such as the place of death and selection of treatment. This fact is important for medical practitioners. All medical practitioners must take into account the great extent to which confidence and reliance is placed in them and on their decision making. Among the patients who had an ongoing relationship with the medical profession and source of care, many reported feeling confident that they had a reliable doctor (or medical institution) to whom they could leave their end-of-life treatment decisions.

### Limitations

The participants in this investigation were elderly patients who were either hospitalized or who had been receiving medical treatment for a number of years as outpatients of a university hospital. It

is assumed that they actively chose these facilities based on the expertise of the professionals practicing there. This might result in a biased group of patients compared with the elderly population in Japan who have no links with specific hospitals whether as in- or outpatients. Therefore, the data obtained may not represent Japanese elderly people as a whole. While we are confident that we have accurately depicted the views of these participants, and that these depictions likely hold for many elderly Japanese patients, we cannot be certain how common these views are and whether they represent the spectrum of views.

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