ORIGINAL

Japanese elderly individuals wish for enteral tube feeding more strongly for their parents than for themselves

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Abstract : [Introduction] The purpose of this study was to investigate the differences in the preference of enteral tube feeding between elderly inhabitants of Mugi town, Tokushima Prefecture, Japan, and their parents in various physical conditions. [Methods] This population-based questionnaire survey studied 300 randomly selected participants aged 65–80 years. Respondents were to consider a situation where eating was difficult, and were questioned on their desire for tube feeding, using a visual analogue scale (VAS) ranging from "do not want tube feeding (0)" to "want tube feeding (100)." [Results] Valid responses of 103 (34.4%) participants were analyzed. Under conditions of being "healthy," "bedridden," "with dementia," and "bedridden and with dementia," the median (IQR) of the VAS values for the desire for tube feeding were 31.8 (3.3 to 83.8), 19.3 (2.4 to 52.3), 5.2 (0.7 to 18.9), 4.0 (0.3 to 15.2) for respondents and 55.2 (11.6 to 92.2), 48.7 (5.5 to 85.5), 9.0 (1.2 to 46.8), 5.1 (0.1 to 36.5) for parents, respectively. The VAS values for the parents were significantly higher (p=0.001, 0.002, 0.001, and 0.01, respectively for the four conditions described) for the same items. [Conclusion] Surrogate decisions made by family members often differ from what the patients would have desired. J. Med. Invest. 66 : 258-263, August, 2019

Keywords **:** *surrogate decision making, enteral tube feeding, questionnaire survey, visual analogue scale*

INTRODUCTION

The Japanese population has 35 million adults (27.7% of the total population) over the age of 65 years, and this number is expected to increase to 37 million (32.8%) by 2035. (1) Elderly individuals tend to have declining health, often resulting in difficulty with swallowing. Introduction of enteral tube feeding would be considered when it becomes impossible to maintain their life without nutritional support. The decision of whether to introduce enteral tube feeding is one of the most important problems faced by elderly individuals and their families. With this background, the use of advance directives (AD) have become widespread in recent years. In the United States, the prevalence of AD was 21% in 1990 (2) and it was rapidly increasing to about 70% in 2000. (3) In 2013, however, though 70% of the Japanese recognized the importance of leaving written instructions, only 3% actually had these documents ready, (4) which has increased to 10% in 2017. (5) Advance care planning (ACP) (6) is a process that supports adults of all ages and stages of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. In Japan, however, in a survey in 2017, only 3% were familiar with ACP. (5)

A UK guideline states that "in cases where a patient cannot express a wish regarding enteral tube feeding, the doctor must make decisions on enteral tube feeding in the patient's best interest. Consulting widely with all carers and family is essential." (7) In Japan, the Ministry of Health, Labour and Welfare proposed a guideline for end-of life care in 2007, (8) which states that "When the patient's wish is not known, carers should take the following two steps : (1) when a family can guess a patient's wish, the health care providers should follow them ; and (2) when a family cannot guess, the health care providers must make the best decision following detailed discussion with the family." Regarding nutritional therapy, the guidelines of the Japanese Society for Parenteral and Enteral Nutrition state that caution should be taken when considering the introduction of nutritional therapy in individuals with advanced dementia. (9)

However, decision-making is a burden for many families, and significant emotional stress can remain after 6 months. (10) The preliminary discussion did not improve the accuracy rate between patients' preference and surrogates' prediction, (11) and the accuracy rate between the decisions of legally assigned surrogates and the surrogates designated by the patient were not statistically different (68% vs. 69%), (12) but the ACP was found to reduce the burden on the family. (10) In the Japanese questionnaire, only 7.5% individuals wanted to receive tube feeding if bedridden and having dementia. (5) However, even in such physical conditions, enteral tube feeding is often carried out in Japan. (13) Although the usefulness of tube feeding in cases of terminal illness may depend on the situation, and there is no conclusive opinion, (14) families appear to have expectations from tube feeding even if the health conditions do not improve after 3 months from the start. (15)

To the best of our knowledge, there is no report that considered surrogate decision making for enteral tube feeding for Japanese and only one report on artificial hydration and nutrition (AHN) for Japanese. (16) A questionnaire survey at a public seminar

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(n = 176, containing 35 medical staffs) asked participants about the desire for AHN when oral intake became difficult, for themselves and their families. Although only 46% wished for AHN in their own case, 71% of them chose it for their parents or family members. Therefore, while respondents did not wish AHN for themselves, they wished it for their families, which suggests that surrogate decisions are often not what the patient would have wanted. However, this report has some limitations. First, it does not distinguish between those who wished enteral tube feeding from those who wished AHN, which includes not only enteral tube feeding but also hydration. Second, the cause of the difficulty in oral ingestion is obscure. Third, no statistical analysis was performed.

Therefore, we conducted this study to compare the desire for nutrition by tube feeding among the elderly inhabitants of Mugi town of the the Tokushima Prefecture, Japan, for themselves versus for their parents in various physical conditions.

MATERIALS AND METHODS

This population-based questionnaire survey was conducted in Mugi town in the southern part of the Tokushima Prefecture, Japan. It is a small seaside town with a population of 4763 of which 41.9% are over the age of 65 years. With the cooperation of the town hall, 300 people were chosen from a total of 1601 residents aged 65 to 80 years from the July 2015 voter list, using a systematic sampling method. We mailed the questionnaire and collected anonymous responses by October 15, 2015. This study was conducted according to the guidelines of the Declaration of Helsinki. Participants were informed about the study design and returned the questionnaires based on their free will.

The questionnaire had questions on age, sex, past medical history, present activities of daily living (ADL), hospital visits, and bereavement of parents. The participants were asked to imagine a situation where they were in a nursing home, and it was difficult for them to eat from the mouth. They were then asked if they would opt for tube feeding by nose or stomach, for maintenance of life, in the following physical conditions : (A) healthy except for eating difficulty, (B) bedridden but can communicate, (C) has dementia and unable to communicate, and (D) bedridden with dementia and unable to communicate. The responses were recorded using a visual analogue scale (VAS) ranging from "do not want tube feeding : 0 to "want tube feeding : 100." We then asked the same question if these situations were to arise in their parents. When the physical condition of the respondent was A, B, C, and D, it was described as Rsp-A, Rsp-B, Rsp-C, and Rsp-D, respectively. Likewise, when the physical condition of the respondent's parent was A, B, C, and D, it was described as Ps-A, Ps-B, Ps-C, and Ps-D, respectively. The length of the line segment for VAS was 75.1 mm and 78.1 mm in the case of the respondents themselves and their parents, respectively, which was converted to 100 each.

Statistical analyses were performed using IBM SPSS Statistics version 24 (IBM Corp, Armonk, NY, USA). Age indicated as mean ± SD was categorized into 3 groups (in years) : < 70, 70-74, and ≥ 75 years. The VAS values were indicated as a median and interquartile range (IQR). Wilcoxon signed rank test was used to compare the VAS values in the case of respondents themselves with their parents and for each physical condition. The Kruskal-Wallis test was performed to compare the results between different age categories and VAS values. The Mann-Whitney test was used for comparison of each VAS value based on sex, ADL, and past medical history. In comparison between the different physical condition groups, $p < 0.083$ was made significant by the Bonferroni method, and all other results were considered significant at $p < 0.05$.

RESULTS

Characteristics of the respondents

Three hundred questionnaires were mailed to selected candidates on August 25, 2015. While one was returned because of unknown address, 143 responses (response rate : 47.8%) were collected by October 15, 2015. We excluded 40 responses because of at least one unanswered VAS question (range of unanswered questions : 2-8, the most common being 8 questions with 23 responses), and finally had a total of 103 valid responses (valid response rate : 34.4%). The characteristics of the respondents are summarized in Table 1. The mean age was 70.2 ± 7.8 years while the median age was 70 (IQR 67–74) years. The study population included 39 men (37.9%) and 64 women (62.1%).

Table 1. Characteristics of the respondents

	n	%
Total number	103	100.0
Age (years)		
65≤ < 70	47	45.6
70≤ < 75	31	30.1
75≤ ≤80	25	24.3
Women	64	62.1
Activity of daily living		
Go out by using transportation (J1)	84	81.6
Can move in the neighborhood (J2)	17	16.5
Need help for going out	0	0.0
Bedridden	0	0.0
Unanswered	2	1.9
Past history		
Hypertension	47	45.6
Diabetes mellitus	17	16.7
Hyperlipidemia	16	15.5
Cancer	9	8.7
Stroke	7	6.8
Fracture of the foot	5	4.9
Ischemic heart disease	4	3.9
Pneumonia	4	3.9
Heart failure	0	0.0
Renal failure required for dialysis	0	0.0
Both parents alive	6	5.8

The past medical history included hypertension [47 (45.6%)], diabetes [17 (16.7%)], hyperlipidemia [16 (15.5%)], cancer [9 (8.7%)], stroke [7 (6.8%)], fracture of the foot [5 (4.9%)], pneumonia [4 (3.9%)], ischemic heart disease [4 (3.9%) (2 angina pectoris and 2 myocardial infarction)], heart failure [0], and dialysis [0]. The responses to current ADL showed that 84 respondents (81.6%) could go out by themselves using transportation (J1), 17 (16.5%) could move around in the neighborhood (J2), and 2 left the question unanswered, indicating that most of the respondents were self-supporting. While 77 (74.8%) respondents indicated that they were visiting the hospital, 6 (5.8%) of them were not visiting the hospital, and 20 (19.4%) of them left the question unanswered. While 97 (94.2%) respondents had lost at least one parent, 6 (5.8%) respondents had not lost their parents.

The desire for tube feeding

The median (IQR) VAS values for the desire for tube feeding in physical conditions Rsp-A, Rsp-B, Rsp-C, and Rsp-D were

31.8 (3.3 to 83.8), 19.3 (2.4 to 52.3), 5.2 (0.7 to 18.9), and 4.0 (0.3 to 15.2), respectively (Fig. 1a). A comparison of Rsp-A vs. Rsp-B, and Rsp-B vs. Rsp-C revealed that the VAS values became significantly lower as the physical condition worsened ($p < 0.001$, $p < 0.001$, respectively). Rsp-C vs. Rsp-D did not show significant results, using the Bonferroni method ($p = 0.048$). However, the median (IQR) VAS values for the desire for tube feeding in case of parents : Ps-A, Ps-B, Ps-C, and Ps-D were 55.2 (11.6 to 92.2), 48.7 (5.5 to 85.5), 9.0 (1.2 to 46.8), and 5.1 (0.1 to 36.5), respectively (Fig. 1b). As seen with the respondents, the VAS values became lower as the physical condition worsened [Ps-A vs. Ps-B ($p = 0.001$), Ps-B vs. Ps-C ($p < 0.001$), Ps-C vs. Ps-D ($p < 0.001$)]. When comparing the same items in case of self and parents (Rsp-A vs. Ps-A, Rsp-B vs. Ps-B, Rsp-C vs. Ps-C, and Rsp-D vs. Ps-D), the VAS values for the desire for tube feeding in the case of parents were significantly stronger ($p = 0.001$, 0.002, 0.001, 0.01, respectively) (Table 2).

Fig 1. The VAS values for the desire for enteral tube feeding. The VAS values significantly decrease as the physical condition worsens except in Rsp-D. Data are presented as box plots, where the boxes represent the 25th to 75th percentiles, the lines within the boxes represent the median, and the lines outside the boxes represent the last data point that occurs below the 25th or above the 75th percentile and their respective inner fence (1.5 times the interquartile distance). P-values are calculated using the Wilcoxon signed rank test. After correcting by the Bonferroni method, $p < 0.083$ is considered significant.

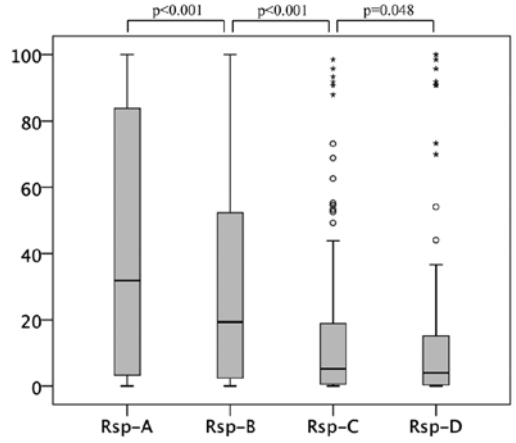

Fig.1a : Respondents with difficulty in eating under the following conditions:
Rsp-A) healthy except for eating difficulty
Rsp-B) bedridden but can communicate
Rsp-C) have dementia and unable to communicate
Rsp-D) bedridden, have dementia and unable to communicate

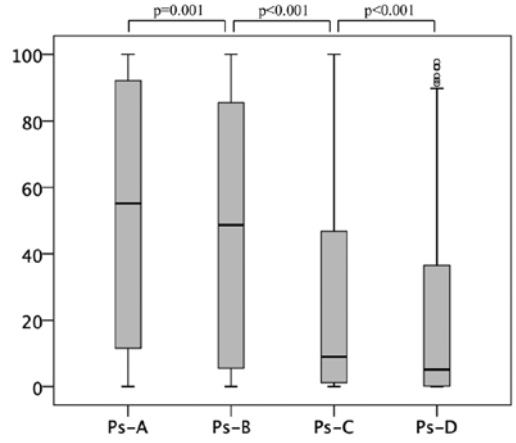

Fig. 1b : Parents with difficulty in eating under the following conditions:
Ps-A) healthy except for eating difficulty
Ps-B) bedridden but can communicate
Ps-C) have dementia and unable to communicate
Ps-D) bedridden, have dementia and unable to communicate

Table 2. VAS values of the desire for tube feeding in respondents and their parents

Physical condition	Desire for tube feeding		p value
	Respondents (n=103)	Parents (n=103)	
Healthy except for eating difficulty (A)	31.8 (3.3 to 83.8)	55.2 (11.6 to 92.2)	0.001
Bedridden (B)	19.3 (2.4 to 52.3)	48.7 (5.5 to 85.5)	0.002
Dementia (C)	5.2 (0.7 to 18.9)	9.0 (1.2 to 46.8)	0.001
Bedridden and dementia (D)	4.0 (0.3 to 15.2)	5.1 (0.1 to 36.5)	0.01

P-values were calculated using Wilcoxon signed ranks tests.
In all cases, the desire for tube feeding for parents was higher than that for the respondents themselves.

Relationship with past medical history

When respondents had a history of stroke, they had significantly lower VAS values for the desire for tube feeding for their parents in conditions Ps-A and Ps-B ($p = 0.04$ and 0.004, respectively) (Table 3). Based on ADL, 4 out of 7 stroke patients (57.1%) were categorized as J1 and 3 (42.9%) as J2. Compared to individuals with no past history of a stroke who were categorized as J1 [n = 80 (83.3%)], more stroke patients tended to fall into the J2 category [n = 14 (14.6%)] ; 2 (2.1%) individuals (2.1%) did not provide a response ($p = 0.06$, Chi-square test). Conditions Ps-C or Ps-D which indicated higher deterioration of the parents' physical condition did not show any significant difference regardless of respondents' history of stroke. On the other hand, when there was a history of fracture in the foot, both Ps-C and Ps-D were significantly higher ($p = 0.02$, 0.03, respectively) (Table 4). No respondents had a combined history of both stroke and fracture. There were no significant associations with other conditions in the medical history.

Table 3. The VAS values of the desire for tube feeding for parents based on the respondent's history of stroke

Physical condition	Desire for tube feeding		p value
	Stroke		
	Yes (n=7)	No (n=96)	
Healthy except for eating difficulty (A)	2.7 (0.9 to 56.5)	55.6 (13.1 to 94.6)	0.04
Bedridden (B)	0.3 (0.0 to 22.9)	51.9 (7.7 to 87.4)	0.004
Dementia (C)	1.4 (1.2 to 17.1)	9.4 (1.2 to 47.6)	0.3
Bedridden and dementia (D)	1.5 (0.1 to 9.0)	7.6 (0.4 to 37.5)	0.2

Table 3. The VAS values [median (IQR)] for the desire for tube feeding for parents based on whether the respondent has a history of stroke. P-values were calculated using the Mann-Whitney U test. Respondents who experienced a stroke desired for enteral tube feeding less than the others even though they were healthy except for eating (underlined).

Table 4. The VAS values for the desire for tube feeding for parents based on the respondent's history of foot fracture

Physical condition	Desire for tube feeding		p value
	Fracture of the foot		
	Yes (n=5)	No (n=98)	
Healthy except for eating difficulty (A)	48.7 (16.7 to 86.6)	55.3 (10.2 to 92.2)	0.9
Bedridden (B)	69.3 (48.0 to 88.1)	48.6 (3.8 to 85.2)	0.2
Dementia (C)	47.4 (36.0 to 94.5)	8.2 (1.2 to 44.8)	0.02
Bedridden and dementia (D)	37.1 (25.9 to 46.1)	4.3 (0.1 to 33.6)	0.03

Table 4. The VAS values [median (IQR)] for the desire for tube feeding for parents classified based on whether the respondent has a history of foot fracture. P-values were calculated using the Mann-Whitney U test. Respondents who experienced a foot fracture desired for enteral tube feeding more than the others even though they had dementia (underlined).

Other items

Men had higher VAS values for normal cognitive functions when compared to women : 51.5 vs. 14.9 (IQR 9.9 to 91.4 vs. 1.7 to 60.3) for Rsp-A, and 30.6 vs. 8.0 (IQR 7.4 to 89.3 vs. 1.5 to 51.0) for Rsp-B ($p = 0.02$, 0.03, respectively) (not shown in table). In Rsp-C, Rsp-D, and Ps-A to Ps-D, there were no significant differences between men and women. The age category of the respondents, hospital visits, and bereavement of parents did not affect each item (not shown in table).

DISCUSSION

In any of the physical conditions described, the VAS values for parents were significantly higher than for the respondents themselves (Table 2), though the desire for tube feeding was reduced as the physical condition worsened.

Some reports draw comparisons between older adults and the surrogates. Bravo and colleagues conducted randomized control trial interventions (workshop) among elderly people over the age of 70 who could make decisions and the individuals they choose as their surrogates. (17) In the baseline before intervention, in a hypothetical case of light to moderate stroke and severe dementia, the family wished for tube feeding more strongly than elderly people themselves. Hare *et al*. also reported that families strongly wished for tube feeding. (18) From these results, it can be said that families desire more tube feeding than patients, and from our results, the families desire for tube feeding more strongly for patients than for themselves. As indicated in the guidelines, decision-making in cases where the patient himself/herself cannot judge should be decided after consultation between the family and the medical staff, so that enteral tube feeding is introduced if the family strongly wish for tube feeding. Without AD, there are significantly more cases that would receive artificial respiration or tube feeding and to die in ICU, (3) and there are significantly more cases that would receive all care possible. (19) In Japan, there are few implementations of ACP and AD, (5) which would be the most important reason for the frequent administration of tube feeding to patients with dementia in Japan. Other factors may include the recognition of indications for tube feeding depending on the medical practitioner, inadequate guidelines for tube feeding, and the fact that the medical expenses are relatively inexpensive.

When becoming bedridden or losing communication, the desire for tube feeding decreases for both respondents and their parents (Figure 1), supporting the guidelines which recommend considering individual circumstances. (7-9) In the case of patients with dementia who cannot communicate, the impact of being bedridden too was small. In the Ministry of Health, Labor and Welfare's "Awareness Survey Report on Medical Care at the Last Phase of Life," (5) six health stages have been described, and participants were questioned about the desired medical care for each stage. Three of the six stages were such where no tube feeding is necessary, or tube feeding was already ongoing. Therefore, the survey assessed the desire for tube feeding in the remaining three health stages which included end-of-life cancer state which is inconvenient but firm judgment is possible, severe heart disease, and advanced dementia. Nasal nutrition for these three stages was desired by 9.8%, 9.0%, 7.5% of the participants, respectively, while gastrostomy was desired by 6.0%, 5.5%, 4.8%, respectively, clearly showing that only a few people wanted tube feeding. The desire for tube feeding decreases in patients with advanced dementia compared to those in terminal stages of cancer or with severe heart disease, which is consistent with the decline of the VAS value in Rsp-C compared to Rsp-B in our study (Fig. 1a). In the report by Bravo *et al*., even in the case of severe dementia, the family wanted more tube feeding than the principal, but a small number. (17) These findings suggest that it is important to be able to communicate as a reason for prolonging survival. Although caution should be taken when considering the introduction of nutritional therapy in individuals with advanced dementia according to the Japanese guidelines, (9) in Canada, (20) the United States, (21, 22) and Europe, (23) guidelines recommend that a feeding tube should not be inserted because, in patients with advanced dementia, enteral tube feeding does not improve survival, nor does it improve the individual's comfort level (24, 25). In order to reduce unnecessary tube feeding in situations where the individual does not desire for it and is not appropriate medical care, familiarization of ACP and spreading information to medical staff are considered important.

In the case of respondents with a past history of stroke, the desire for enteral tube feeding for parents was significantly low level even in situations with mild disorders (Table 3). Conversely, respondents with a past history of a foot fracture had higher VAS values in spite of dementia (Table 4). The reason for this difference may be the difference in the ability to predict the prognosis. (26) Stroke can cause a permanent disorder, whereas a fracture of the foot does not result in permanent disability in most cases. Therefore, respondents with a past history of stroke might consider disability seriously, while those with a past history of fracture might not. Therefore, the past medical history can make the desire for tube feeding high or low regardless of the current physical condition, pointing to the importance of respecting individual thinking. However, careful attention should be paid to this interpretation because the number of people with these past histories was small. There may be other aspects of the past medical histories such as experiences with hospitalization or planning before the disease, but it was difficult to assess them in this study. Also, it was impossible to evaluate people with both medical histories since there were no such patients.

This population-based survey has some limitations. First, the valid response rate was 34%, and most of the respondents were independent based on their current ADL (98% independent, 2% unanswered). Therefore, these results reflect the feelings for tube feeding in mostly healthy individuals. Second, the questions on tube feeding are based on the assumption of a time when it would be needed in case of both the respondents and parents. The opinions expressed in the survey could change when the situation becomes real. (27) While it is quite difficult for the same person to be in states Rsp-A and Rsp-B and to investigate it prospectively, it is also difficult to get their opinion once dementia

sets in (Rsp-C and Rsp-D). Likewise, it is impossible to compare the cases of self and of parents. Third, we adopted a mailing method and therefore it is unknown whether each respondent could assume the same physical situation. Fourth, repetitive measurements of nonparametric data have no established test to verify interactions. However, the age category of respondents, the presence or absence of hospital visits, and bereavement of parents had no significant influence on the VAS values, which suggest that these items only have a few interactions with the VAS values for the desire for tube feeding. While men desired more tube feeding in the conditions of Rsp-A and Rsp-B, they did not desire it for the parents. Finally, since the length of the line segment for respondents and parents was 75.1 mm and 78.1 mm, respectively, it was converted into 100 in each case. However, as each question was on a different page, the influence on the replies was assumed to be small.

In conclusion, the results of this study indicate that family members who make surrogate decisions for enteral tube feeding tend to desire treatments that the patients themselves would not want. It is, therefore, necessary that the medical staff keep this fact in mind when making decisions with surrogates.

CONFLICT OF INTERESTS-DISCLOSURE

None of the authors have any conflicts of interest to declare.

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