*The Journal of Nutrition, Health & Aging©*
*Volume 18, Number 5, 2014*

# PERCUTANEOUS ENDOSCOPIC GASTROSTOMY (PEG) TUBES ARE PLACED IN ELDERLY ADULTS IN JAPAN WITH ADVANCED DEMENTIA REGARDLESS OF EXPECTATION OF IMPROVEMENT IN QUALITY OF LIFE

M. NAKANISHI, K. HATTORI

Institute for Health Economics and Policy, 1-5-11 Nishishinbashi, Minato-ku Tokyo, 105-0003 Japan. Corresponding author: Miharu Nakanishi, PhD, Institute for Health Economics and Policy, 1-5-11 Nishishinbashi, Minato-ku Tokyo, 105-0003 Japan. Tel: +81 (3) 3506-8529; FAX: +81 (3) 3506-8528; E-mail: mnakanishi-tky@umin.ac.jp

**Abstract:** *Background:* The Japan Geriatrics Society published a guideline on the decision-making process for health care for the elderly in June 2012, noting that withholding or withdrawing feeding tubes are treatment options that should be discussed during the decision-making process. Arguments against the guideline posit that the insertion of a percutaneous endoscopic gastrostomy (PEG) tube feeding may improve quality of life (QOL) for elderly adults and their relatives. *Objectives:* The aim of the present study was to explore (a) expected outcomes with PEG tube placement and (b) outcomes from PEG tube feeding in long-term care settings among elderly adults with advanced dementia in Japan. *Design:* This study was conducted using a cross-sectional study design. *Setting:* A total of 381 hospitals and 985 long-term care facilities provided sets of completed questionnaires. *Participants:* There were 1 199 hospital patients and 2 160 long-term care patients aged 65 years or older with PEG tube placement included in the analysis. *Measurements:* The nurses or physicians at each hospital provided information on the level of dementia at the time of PEG tube placement and on the expected outcomes of PEG tube feeding for elderly hospital patients. The nurses or other direct care workers at each facility provided information on the level of dementia and outcomes from PEG tube feeding for the long-term care patients. *Results:* In the hospital patient group, 62.9% of patients had advanced dementia. PEG tube feeding was expected to prolong survival for 51.1% of hospital patients with advanced dementia. Improved QOL was expected for 39.1% of them. In the long-term care patient group, 61.7% of patients had advanced dementia. The rate of patients enjoying their own lives was lower in long-term care patients who had advanced dementia (4.2%) than in the other patients (16.4%). Approximately 60% of relatives reported satisfaction with the QOL of the patients, both in the long-term care patients with advanced dementia and the other patients. *Conclusion:* Our results question the assumption that PEG tube feeding may improve QOL among elderly adults with advanced dementia. The national health policy should explore an approach to help patients, relatives, and practitioners make decisions about feeding options.

**Key words:** Dementia, percutaneous endoscopic gastrostomy, quality of life, tube feeding.

## Introduction

As the number of older adults increases in Western countries, artificial nutrition and hydration procedures have become common (1-3). Patients with advanced dementia frequently develop problems with eating. Percutaneous endoscopic gastrostomy (PEG) tubes are widely placed in patients with dementia (4-7). However, several studies have questioned the benefit of PEG tube feeding in patients with advanced dementia (1, 8-15).

Japan is also confronting a rapid increase in the number of frail elderly patients and the issue of PEG placement in patients with dementia. The All Japan Hospital Association estimated the number of elderly patients with PEG tube feeding to be as high as 256 555 in March 2011: 138 589 in hospitals, 89 096 in residential care under the public Long-Term Care Insurance (LTCI) program, and 28 870 in home health environments (16). The national statistics for September 2010 also indicated the proportion of residents by type of LTCI residential care: special nursing homes (8.3%), geriatric intermediate care facilities (6.0%), and medical facilities (26.2%) (17). The rate of tube feeding has been greater among residents of nursing homes in Japan than in Australia (0.9%) (18), Canada (1.2%) (19), Denmark (0.5%) (20), and the United States (5.38%) (21). The Japan Geriatrics Society published a guideline on the decision-making process for health care for the elderly in June 2012, noting that withholding or withdrawing feeding tubes are treatment options that should be included in the decision-making process that involves professionals, patients, and relatives (22). Arguments against the guideline include the notion that the decision to insert or withdraw a feeding tube is influenced by strong family emotions, religious sentiments, social traditions, and public opinion (23) and that PEG tube feeding may improve the quality of life (QOL) of patients and their relatives (24). However, no studies have yet examined the aim of PEG tube placement in clinical practice and the outcomes with PEG tube feeding among elderly adults in Japan with advanced dementia.

The aim of the present study was to explore (a) the expected outcomes of patients with PEG tube placement and (b) the outcomes from PEG tube feeding in long-term care settings of elderly adults with advanced dementia in Japan.

*Received July 12, 2013*
*Accepted for publication September 26, 2013*

## Methods

We employed a cross-sectional study design. Our study sample consisted of two groups: a hospital patient group and a long-term care patient group.

### *Hospital patients*

Subject facilities consisted of 3 000 hospitals in Japan selected at random from those in the Wellness Database System, a nationwide online database. In April 2012, of the 8 658 hospitals in Japan, 7 587 had general (acute) beds or sanatorium (long-term) beds. Among these hospitals, 3 000 (approximately 40%) were contacted at random to participate in the study.

Hospital patients were randomly selected in each hospital from those aged 65 years or older with PEG tube placement during the 6-month period of April to September 2012. To provide similar representation across hospitals, a maximum of five patients per hospital were enrolled. A total of 802 hospitals (26.7%) responded to the survey; of these, 391 hospitals had no eligible patients during the study period. A total of 1 507 questionnaires were collected from the remaining 411 hospitals. From the 1 507 questionnaires collected, the following patients were excluded: 36 who were aged 64 years or younger and 272 who provided incomplete information. The final sample consisted of the remaining 1 199 patients (79.6% of 1 507) from 381 hospitals (12.7% of 3 000). The final sample had a younger age ($t[337.359] = 5.047$, $p < 0.001$) and lower level of physical dependence ($Z = 3.405$, $p = 0.001$) than the patients who were excluded.

### *Long-term care patients*

Residential services under the LTCI program in Japan include care medical facilities, special nursing homes, and geriatric intermediate care facilities. Care medical facilities are for residents who require significant medical care. Special nursing homes are facilities for people who are stable but require regular nursing care and are the only facilities available for permanent residence. Geriatric intermediate care facilities are for residents who need only light care, require rehabilitation, and are expected to be discharged within three months. The subject facilities consisted of 1 700 special nursing homes, 1 000 geriatric intermediate care facilities, 450 care medical facilities, and 1 500 outreach nursing providers in Japan, which were all identified using the Welfare and Medical Service Network System (WAM-NET), a nationwide online database. In April 2012, Japan had a total of 5 676 special nursing homes, 3 382 geriatric intermediate care facilities, 1 500 care medical facilities, and 5 119 outreach nursing providers. Of these, approximately 30% were contacted at random to participate in the study.

Long-term care patients were randomly selected in each facility from those aged 65 years or older with PEG tube placement. To provide similar representation across facilities, a maximum of three patients per facility were enrolled. A total of 2 858 questionnaires from 1 126 facilities (24.2%) were collected. Among the 2 858 questionnaires collected, the following patients were excluded: 87 who were aged 64 years or younger and 611 who provided incomplete information. The final sample consisted of the remaining 2 160 patients (75.6% of 2 858) from 985 facilities (21.2% of 4 650). The final sample had a younger age ($t [719.349] = 8.273$, $p < 0.001$) than the patients who were excluded.

### *Measurements*

The questionnaire survey was administered during a 5-week period from December 13, 2012, to January 16, 2013. A set of paper questionnaires was mailed to each subject hospital or facility. Completed questionnaires were also collected by mail. Each hospital was asked to distribute the questionnaires to nurses or physicians, who then read the instructions and rated the questions independently. Each long-term care facility was asked to distribute the questionnaires to nurses or other direct care workers, each of whom independently read the instructions and rated the questions. The set of questionnaires included an introductory section that explained the purpose of the study, described the voluntary nature of participation, and provided an assurance of anonymity for the elderly adults and respondent staff members.

The questionnaire collected information on patient age, gender, indication for PEG tube placement, level of physical dependence, level of dementia according to the LTCI standards, previous place of residence, and outcomes of PEG tube feeding. Outcomes of PEG tube feeding in the hospital patient group used one question regarding the practitioner assessment with four categories: (a) PEG tube feeding was expected to improve QOL; (b) PEG tube feeding was expected to prolong survival without improving QOL; (c) PEG tube feeding was expected neither to improve QOL nor to prolong survival; or (d) PEG tube feeding would lead to undetermined outcomes in a patient. Responses were recoded as two categories because of high rates of "PEG tube feeding was expected to improve QOL" and "PEG tube feeding was expected to prolong survival without improving QOL" (1 = with expected improvement in QOL; 0 = without expectation of improvement in QOL). Outcomes of the long-term care patient group assessed presence of six benefits and three disadvantages of PEG tube feedings among the elderly adults after PEG tube placement. Each item was dichotomous for the presence of the outcome measurement (1 = reported; 0 = not reported). These outcome measurements were reviewed by an expert panel, including researchers, medical practitioners in hospitals, and professional caregivers in long-term care settings (Table 3). The level of physical dependence ranged from 1 to 4: 1 = independent in daily life; 2 = homebound; 3 = bedbound; and 4 = completely bedbound. The level of dementia ranged from 1 to 6: 1 = no symptom of dementia; 2 = independent in daily life; 3 = independent with supervision; 4 = some problems in communication and

requiring personal care; 5 = frequent problems in communication and usually requiring personal care; and 6 = always requiring medical care. The scale of level of dementia has shown fair consistency with the scores on the Mini Mental State Examination (MMSE) and Hasegawa Dementia Scale-Revised (HDS-R) (25). In the present study, advanced dementia was defined as a score of 5 or 6, equivalent to an MMSE score < 10. The questionnaire for the patient group also collected information on the reason for hospitalization, the patient's and relative's consent to PEG tube placement, the prospect of the resumption of oral feeding after discharge, and discharge destination (including scheduled discharge for inpatients at the time of assessment). The questionnaire for the long-term care patient group assessed the current use of oral feeding. The questionnaire for the long-term care patient group also included duration of PEG tube feeding. However, many respondents did not indicate the patients' duration (1 023 of 2 160, 47.4%). Therefore, duration was excluded from the analysis.

Participating hospitals and facilities were not required to sign consent forms; their return of the questionnaire implied consent. To preserve respondent anonymity, identification numbers were assigned to hospitals and facilities, and the questionnaires did not collect demographic information for individual respondent staff members. The study was approved by the Institutional Review Board of the Institute for Health Economics and Policy, Japan (H24–008, approval on November 26, 2012).

***Analysis***

Differences between the patients with advanced dementia and the other patients in each group were analyzed based on the patient's age, gender, indication for PEG tube placement, level of physical dependence, oral feeding, previous place of residence, and outcomes from PEG tube feeding.

Multiple logistic regression analysis in the hospital patient group was performed using the rate of patients in whom PEG tube feeding was expected to improve QOL as the dependent variable and the presence of advanced dementia as the independent variable. The independent variables also included age, gender, indication for PEG tube placement, level of physical dependence, and prospect for resumption of oral feeding. Although there were significant differences in previous place of residence and discharge destination between the patients with advanced dementia and the other patients, these variables were excluded from the independent variables due to small sample sizes for some categories. Indication of dementia was also excluded because of inter-correlation with advanced dementia.

Multiple logistic regression analysis in the long-term care patient group was performed using the rate of outcome measurement as the dependent variable and the presence of

**Table 1**

Summary characteristics of 1 199 hospital patients with percutaneous endoscopic gastrostomy (PEG) tube placement in Japan

| Mean (SD) or N (%) | Advanced dementia Yes (N = 754) | No (N = 445) | Test statistic | P-value |
|---|---|---|---|---|
| Age | 82.6 (7.3) | 79.5 (7.8) | t [880.558] = 6.871 | 0.001 |
| Gender, male | 315 (41.8) | 275 (61.8) | $\chi 2$ [1] = 44.878 | 0.001 |
| Hospitalization was aimed at PEG | 172 (22.8) | 81 (18.2) | $\chi 2$ [1] = 3.571 | 0.059 |
| Indication for PEG | | | | |
| Aspiration pneumonia | 304 (40.3) | 160 (36.0) | $\chi 2$ [1] = 2.246 | 0.134 |
| Dementia | 225 (29.8) | 47 (10.6) | $\chi 2$ [1] = 59.303 | 0.001 |
| Cerebrovascular diseases | 341 (45.2) | 160 (36.0) | $\chi 2$ [1] = 9.887 | 0.002 |
| Dehydration and malnutrition | 168 (22.3) | 96 (21.6) | $\chi 2$ [1] = 0.082 | 0.775 |
| Level of physical dependence (1-4) | 3.8 (0.4) | 3.1 (1.0) | t [523.054] = 13.850 | 0.001 |
| Prospect for resumption of oral feeding | 133 (17.6) | 173 (38.9) | $\chi 2$ [1] = 66.400 | 0.001 |
| The patient indicated his/her consent to PEG | 117 (15.5) | 245 (55.1) | $\chi 2$ [1] = 207.571 | 0.001 |
| A relative indicated his/her consent to PEG | 745 (98.8) | 434 (97.5) | $\chi 2$ [1] = 2.788 | 0.095 |
| Previous place of residence | | | $\chi 2$ [3] = 67.521 | 0.001 |
| Hospital[a] | 195 (25.9) | 97 (21.8) | | |
| Nursing home[b] | 214 (28.4) | 59 (13.3) | | |
| Other facility | 67 (8.9) | 23 (5.2) | | |
| Home | 278 (36.9) | 266 (59.8) | | |
| Discharge distribution | | | $\chi^2$ [3] = 45.106 | 0.001 |
| Hospital | 312 (41.4) | 182 (40.9) | | |
| Nursing home | 211 (28.0) | 81 (18.2) | | |
| Other facility | 131 (17.4) | 59 (13.3) | | |
| Home | 100 (13.3) | 123 (27.6) | | |

The degree of freedom is included in [ ]; a. Hospital includes care medical facility; b. Nursing home includes special nursing home and geriatric intermediate care facility.

**Table 2**
Summary characteristics of 2 160 long-term care patients with percutaneous endoscopic gastrostomy (PEG) tube placement in Japan

| Mean (SD) or N (%) | Advanced dementia Yes (N = 1333) | No (N = 827) | Test statistic | P-value |
|---|---|---|---|---|
| Age | 84.5 (7.7) | 82.4 (8.1) | t [1681.946] = 6.216 | 0.001 |
| Gender, male | 301 (22.6) | 306 (37.0) | $\chi^2$ [1] = 52.528 | 0.001 |
| Indication for PEG | | | | |
| Aspiration pneumonia | 447 (33.5) | 264 (31.9) | $\chi^2$ [1] = 0.600 | 0.439 |
| Dementia | 346 (26.0) | 117 (14.1) | $\chi^2$ [1] = 42.262 | 0.001 |
| Cerebrovascular diseases | 652 (48.9) | 402 (48.6) | $\chi^2$ [1] = 0.019 | 0.891 |
| Dehydration and malnutrition | 224 (16.8) | 152 (18.4) | $\chi^2$ [1] = 0.881 | 0.348 |
| Level of physical dependence (1-4) | 3.9 (0.4) | 3.5 (0.7) | t [1142.201] = 14.554 | 0.001 |
| Current use of oral feeding | 188 (14.1) | 279 (33.7) | $\chi^2$ [1] = 116.087 | 0.001 |
| Previous place of residence | | | $\chi^2$ [3] = 18.375 | 0.001 |
| Hospital[a] | 22 (1.7) | 17 (2.1) | | |
| Nursing home[b] | 708 (53.1) | 369 (44.6) | | |
| Other facility | 77 (5.8) | 40 (4.8) | | |
| Home | 526 (39.5) | 401 (48.5) | | |
| Current place of residence | | | $\chi^2$ [3] = 82.545 | 0.001 |
| Care medical facility | 719 (53.9) | 303 (36.6) | | |
| Special nursing home | 243 (18.2) | 253 (30.6) | | |
| Geriatric intermediate care facility | 133 (10.0) | 63 (7.6) | | |
| Home | 238 (17.9) | 208 (25.2) | | |

The degree of freedom is included in [ ]; a Hospital includes care medical facility; b Nursing home includes special nursing home and geriatric intermediate care facility.

advanced dementia as the independent variable. The independent variables also included age, gender, indication for PEG tube placement (except for dementia), level of physical dependence, and current use of oral feeding. The outcome measurements with significant differences between the two groups were used as independent variables in each multiple logistic analysis.

All statistical analyses were conducted using SPSS for Windows, v. 20.0 (IBM SPSS Japan, Tokyo, Japan). The significance level was set at 0.05 (2-tailed).

## Results

### *Individual characteristics of the hospital and long-term care patient groups*

Table 1 shows the individual characteristics for the hospital patient group. There were 754 patients (62.9%) who had advanced dementia. The patients with advanced dementia had a significantly older mean age, less common male sex, a higher rate of indication of dementia and cerebrovascular disease, greater physical dependence, lower prospects for the resumption of oral feeding, and a lower rate of the presence of patient consent (Table 1).

Table 2 shows the individual characteristics for the long-term care patient group. There were 1 333 patients (61.7%) who had advanced dementia. The patients with advanced dementia had a significantly older mean age, less common male sex, a higher rate of indication of dementia, greater physical dependence, lower rate of current use of oral feeding, and a lower rate of the presence of patient consent (Table 2).

Table 3 presents the outcome measurements of the hospital patient group and the long-term care patient group. The rate of expectation of prolonged survival was significantly greater among hospital patients with advanced dementia than the other patients. Fewer long-term care patients with advanced dementia reported improvement of nutrition status and fewer enjoyed their life after PEG tube placement. In contrast, a majority of relatives reported being satisfied with the QOL of the patients' lives, regardless of the presence of advanced dementia among long-term care patients. There were no significant differences in the rates of other benefits and disadvantages from PEG tube feeding between the patients with advanced dementia and the other patients (Table 3).

### *Advanced dementia and outcomes of PEG tube placement*

Table 4 presents the results of the multiple logistic regression analysis of the rate of hospital patients in whom PEG tube feeding was expected to improve QOL. Younger age, the absence of an indication of aspiration pneumonia, less physical dependence, and prospects for the resumption of oral feeding were significantly associated with an expectation of improved QOL. The rate of expected QOL improvement did not vary with the presence of advanced dementia (Table 4).

In the following multiple logistic regression analysis among long-term care patients, we treated the rates of improved nutrition status and of patients enjoying their own lives.

**Table 3**
Outcome measures of 1 199 hospital patients and 2 160 long-term care patients with percutaneous endoscopic gastrostomy (PEG) tube placement in Japan

| | Advanced dementia | | | |
|---|---|---|---|---|
| **N (%)** | **Yes** | **No** | **Test statistic** | **P-value** |
| ***Hospital patients*** | | | | |
| Expected outcomes of PEG tube feeding | | | $\chi^2[3] = 58.701$ | 0.001 |
| Improvement of quality of life (QOL) | 295 (39.1) | 270 (60.7) | | |
| Prolonged survival without improving QOL | 385 (51.1) | 130 (29.2) | | |
| Neither improved QOL nor prolonged survival | 18 (2.4) | 11 (2.5) | | |
| Undetermined | 56 (7.4) | 34 (7.6) | | |
| ***Long-term care patients*** | | | | |
| Benefits from PEG tube feeding | | | | |
| Improved nutrition status | 279 (20.9) | 266 (32.2) | $\chi^2[1] = 34.143$ | 0.001 |
| Less frequent aspiration pneumonia | 462 (34.7) | 300 (36.3) | $\chi^2[1] = 0.584$ | 0.445 |
| Less assistance was required during mealtime | 117 (8.8) | 82 (9.9) | $\chi^2[1] = 0.790$ | 0.374 |
| Administration of medication was ensured | 812 (60.9) | 508 (61.4) | $\chi^2[1] = 0.056$ | 0.813 |
| The patients enjoyed their own lives | 56 (4.2) | 136 (16.4) | $\chi^2[1] = 94.472$ | 0.001 |
| The relatives were satisfied with the QOL of patients' lives | 781 (58.6) | 514 (62.2) | $\chi^2[1] = 2.698$ | 0.100 |
| Disadvantages from PEG tube feeding | | | | |
| The patient had some episodes of choking or aspiration | 231 (17.3) | 124 (15.0) | $\chi^2[1] = 2.027$ | 0.155 |
| Skin irritation, diarrhea, constipation, or nausea/vomiting | 359 (26.9) | 195 (23.6) | $\chi^2[1] = 3.008$ | 0.083 |
| Long-term care services were less available | 157 (11.8) | 114 (13.8) | $\chi^2[1] = 1.873$ | 0.171 |

The degree of freedom is included in [ ].

**Table 4**
Multiple logistic regression analysis of percutaneous endoscopic gastrostomy (PEG) tube placement with expectation of improved quality of life among 1 109 hospital patients

| | **Odds Ratio[a]** | **95% CI** |
|---|---|---|
| Constant value | 61.396 | |
| Advanced dementia | 0.790 | 0.593-1.051 |
| Age | **0.970** | 0.953-0.987 |
| Gender, male | 1.100 | 0.841-1.439 |
| Indication for PEG | | |
| Aspiration pneumonia | **0.676** | 0.516-0.884 |
| Cerebrovascular diseases | 1.269 | 0.974-1.652 |
| Dehydration and malnutrition | 0.926 | 0.679-1.263 |
| Level of physical dependence | **0.585** | 0.477-0.717 |
| Prospect for resumption of oral feeding | **4.285** | 3.138-5.852 |
| $\chi^2[8]$ | 226.397 | |
| p-value | < 0.001 | |
| Adjusted McFadden Pseudo-$R^2$ | 14.1% | |

The degree of freedom is included in [ ]; a. Odds ratios were calculated as the presence of an expectation of improved quality of life = 1. Bold, significant at 0.05.

Table 5 presents the results of multiple logistic regression analysis of the rate of improved nutrition status among long-term care patients after PEG tube placement. Younger age, the absence of an indication of aspiration pneumonia, and dehydration and malnutrition, less physical dependence, and current use of oral feeding were significantly associated with improved nutrition status after PEG tube placement. The rate of improvement in nutrition status did not vary with the presence of advanced dementia (Table 5).

**Table 5**
Multiple logistic regression analysis of improved nutrition status among 2 160 long-term care patients after percutaneous endoscopic gastrostomy (PEG) tube placement

| | **Odds Ratio[a]** | **95% CI** |
|---|---|---|
| Constant value | 4.734 | |
| Advanced dementia | 0.822 | 0.660-1.024 |
| Age | **0.978** | 0.965-0.991 |
| Gender, male | 1.171 | 0.926-1.480 |
| Indication for PEG | | |
| Aspiration pneumonia | **1.367** | 1.095-1.706 |
| Cerebrovascular diseases | 1.136 | 0.919-1.404 |
| Dehydration and malnutrition | **1.393** | 1.070-1.813 |
| Level of physical dependence | **0.726** | 0.611-0.862 |
| Current use of oral feeding | **2.535** | 1.999-3.214 |
| $\chi^2[8]$ | 157.493 | |
| p-value | < 0.001 | |
| Adjusted McFadden Pseudo-$R^2$ | 6.8% | |

The degree of freedom is included in [ ]; a. Odds ratios were calculated as the presence of improved nutrition status = 1; Bold, significant at 0.05.

Table 6 presents the results of multiple logistic regression analysis of the rate of patients enjoying own lives among long-term care patients after PEG tube placement. Long-term care

patients with advanced dementia showed a lower likelihood of enjoying themselves in life after PEG tube placement. The long-term care patients who enjoyed themselves more were those who had less physical dependence, less indication of dehydration and malnutrition, and currently used oral feeding (Table 6).

**Table 6**
Multiple logistic regression analysis of enjoying one's own life among 2 160 long-term care patients after percutaneous endoscopic gastrostomy (PEG) tube placement

| | Odds Ratio[a] | 95% CI |
|---|---|---|
| Constant value | 0.789 | |
| Advanced dementia | **0.430** | 0.300-0.617 |
| Age | 1.004 | 0.982-1.026 |
| Gender, male | 1.419 | 0.989-2.036 |
| Indication for PEG | | |
| Aspiration pneumonia | 0.693 | 0.474-1.015 |
| Cerebrovascular diseases | 0.885 | 0.631-1.242 |
| Dehydration and malnutrition | **0.552** | 0.340-0.894 |
| Level of physical dependence | **0.505** | 0.407-0.627 |
| Current use of oral feeding | **4.171** | 2.968-5.862 |
| $\chi^2$[8] | 254.617 | |
| p-value | < 0.001 | |
| Adjusted McFadden Pseudo-$R^2$ | 20.3% | |

The degree of freedom is included in [ ]; a. Odds ratios were calculated as the presence of patients enjoying their own lives = 1; Bold, significant at 0.05.

## Discussion

In the hospital patient group, PEG tube feeding was expected to improve QOL in 39.1% of patients with advanced dementia. Prolonged survival was expected in 51.1% of patients with advanced dementia. Some practitioners might believe that PEG tube placement will help to prolong the survival of elderly patients with advanced dementia. A significant difference was observed between clinical practices in Japan and the literature on PEG tube feeding in patients with advanced dementia as well as practices in Western countries (26-28). The multiple logistic regression analysis indicated lower expectation of improved QOL among older patients, those with greater physical dependence, and those with an indication of aspiration pneumonia. These characteristics are associated with high mortality among elderly patients after PEG tube placement (29). Younger age and less physical dependence were also positively associated with improved nutrition status in the long-term care patients after PEG tube placement. Even controlling for these patient characteristics, fewer respondents enjoying their own lives was observed among long-term care patients with advanced dementia after PEG tube placement. Our results questioned the assumption that PEG tube feeding may improve QOL among those with advanced dementia. While use of oral feeding was positively associated with the expectation of improved QOL among hospital patients, improved nutrition status, and enjoying one's own life among long-term care patients, a majority of long-term care patients with advanced dementia did not use oral feeding after PEG tube placement. Furthermore, the rate of patients enjoying their lives was even lower in long-term care patients with dementia than the expectation of improved QOL in hospital patients. The difference between expected outcomes in the hospital patients and outcomes in the long-term care patients may result from a lack of discharge planning in acute care settings. The average length of hospital stay in Japan was 32.0 days in 2011 (30) and has been reported to be longer than other OECD countries (31). A multidisciplinary approach has not been established in the decision-making process on the use of feeding tubes (32). In addition, Japan has no legislation on advanced directive/care planning. The final decision-making process in dementia care typically relies on relatives (33). However, the relatives might not necessary represent the patients' views. The rate of relatives' satisfaction with the QOL of the patients' lives was inconsistent with the rates of patients enjoying their own lives in the long-term care patient group. The decision by Japanese physicians to use PEG tube feeding in elderly patients with severe cognitive impairment is influenced by the national health insurance scheme which allows long-term hospital stays, and the legal barriers that disallows limiting treatment (34). Therefore, solely following the guideline set forth by the Japan Geriatrics Society will fail to limit the unnecessary placement of PEG tubes in elderly patients with advanced dementia. Interventions have been suggested to reduce decisional conflict for surrogates and increase their knowledge of and communication about feeding options with providers. These interventions include a decision aid on feeding options in advanced dementia (35, 36) and an educational program on end of life care and on the feeding management of patients with dementia (37). Oral feeding options can help patients with dementia gain weight (38). The national health policy should explore an approach that will help patients, relatives, and practitioners determine the appropriate feeding options.

These findings should be interpreted in light of the study limitations. While the sample size was large and the response rate was comparable to the hospital and facility response rates obtained in a previous study in Japan (16), there may have been a responder bias. Our study sample consisted of elderly adults with PEG tube placement, so we could not determine the characteristics associated with PEG tube placement in elderly adults with advanced dementia. A cross-sectional design could not validate the hospital practitioners' expectations of predicted QOL in long-term care settings after PEG tube placement. The patient information (sex and previous place of residence) differed between the hospital patient group and the long-term care patient group. Each outcome measurement of the long-term care patients was evaluated by professional caregivers using a single question. Finally, our sampling method did not allow us to control for facility ownership, number of beds, Intensive Care Unit use (5,39), physician specialty (40), and education level of elderly adults (41) and their relatives (42);

these factors have all previously been associated with feeding tube placement.

## Conclusion

The Japan Geriatrics Society published a guideline for the decision-making process in health care for the elderly in June 2012, noting that withholding or withdrawing feeding tubes is a treatment option that should considered by professionals, patients, and relatives together. Arguments against the guideline posit that the use of a PEG tube feeding may increase QOL for elderly adults and their relatives. The present study explored (a) expected outcomes with PEG tube placement and (b) QOL in long-term care settings of elderly adults with advanced dementia and their relatives in Japan. Our results questioned the assumption that PEG tube feeding will improve QOL for elderly adults with advanced dementia. The national health policy should explore an approach to help patients, relatives, and practitioners make appropriate decisions about feeding options in this population.

*Funding source:* This study was part of a research project by the Institute for Health Economics and Policy that was funded by a grant from the Health and Welfare Bureau for the Elderly and the Ministry of Health, Labour, and Welfare in Japan. The sponsor had no involvement in the study design, methodology, recruitment of the subjects, data collection, data analysis, interpretation of the results, or preparation of the manuscript. The authors declare no conflicts of interest.

## References

1. Cervo FA, Bryan L, Farber S. To PEG or not to PEG: a review of evidence for placing feeding tubes in advanced dementia and the decision-making process. Geriatrics 2006;61:30-35
2. Clarfield AM, Monette J, Bergman H, Monette M, Ben-Israel Y, Caine Y, Charles J, Gordon M, Gore B. Enteral feeding in end-stage dementia: a comparison of religious, ethnic, and national differences in Canada and Israel. J Gerontol A Biol Sci Med Sci 2006;61:621-627
3. Vitale CA, Hiner T, Ury WA, Berkman CS, Ahronheim JC. Tube feeding in advanced dementia: an exploratory survey of physician knowledge. Care Manag J 2006;7:79-85
4. Mitchell SL, Kiely DK, Gillick MR. Nursing home characteristics associated with tube feeding in advanced cognitive impairment. J Am Geriatr Soc 2003;51:75-79
5. Mitchell SL, Teno JM, Roy J, Kabumoto G, Mor V. Clinical and organizational factors associated with feeding tube use among nursing home residents with advanced cognitive impairment. JAMA 2003;290:73-80
6. Braun UK, Rabeneck L, McCullough LB, Urbauer DL, Wray NP, Lairson DR, Beyth RJ. Decreasing use of percutaneous endoscopic gastrostomy tube feeding for veterans with dementia-racial differences remain. J Am Geriatr Soc 2005;53:242-248
7. Kurien M, Westaby D, Romaya C, Sanders DS. National survey evaluating service provision for percutaneous endoscopic gastrostomy within the UK. Scand J Gastroenterol 2011;46: 1519-1524
8. Finucane TE, Christmas C, Travis K. Tube feeding in patients with advanced dementia: a review of the evidence. JAMA 1999;282:1365-1370
9. Sanders DS, Carter MJ, D'Silva J, James G, Bolton RP, Bardhan KD. Survival analysis in percutaneous endoscopic gastrostomy feeding: a worse outcome in patients with dementia. Am J Gastroenterol 2000;95:1472-1475
10. Dharmarajan TS, Unnikrishnan D, Pitchumoni CS. Percutaneous endoscopic gastrostomy and outcome in dementia. Am J Gastroenterol 2001;96:2556-2563
11. Murphy LM, Lipman TO. Percutaneous endoscopic gastrostomy does not prolong survival in patients with dementia. Arch Intern Med 2003;163:1351-1353
12. Shah PM, Sen S, Perlmuter LC, Feller A. Survival after percutaneous endoscopic gastrostomy: the role of dementia. J Nutr Health Aging 2005;9:255-259
13. Kuo S, Rhodes RL, Mitchell SL, Mor V, Teno JM. Natural history of feeding-tube use in nursing home residents with advanced dementia. J Am Med Dir Assoc 2009;10:264-270
14. Sampson EL, Candy B, Jones L. Enteral tube feeding for older people with advanced dementia. Cochrane Database Syst Rev 2009;15;(2):CD007209
15. Kimyagarov K, Turgeman D, Fleissig Y, Klid R, Kopel B, Adunsky A. Percutaneous endoscopic gastrostomy (PEG) tube feeding of nursing home residents is not associated with improved body composition parameters. J Nutr Health Aging 2013;17:162-165
16. All Japan Hospital Association (2011) Report on elderly patients in whom PEG tube is placed and management of tube feeding in residential facilities for elderly and home care settings. http://www.ajha.or.jp/voice/pdf/other/110416_1.pdf. Accessed 11 February 2013 (in Japanese)
17. Ministry of Health, Labour and Welfare (2012) Survey of Institutions and Establishments for Long-term Care, 2010. http://www.e-stat.go.jp/SG1 /estat/GL08020103.do?_toGL08020103_&listID=000001086114&requestSender=dsearch. Accessed 26 February 2013 (in Japanese)
18. Department of Health and Ageing (2011) Review of the Aged Care Funding Instrument. http://www.health.gov.au/internet/publications /publishing.nsf /Content/CA25774C001857CACA25788B0006EA4E/$File/ReportReviewofACFI.pdf Accessed 13 September 2013
19. Canadian Institute for Health Information (2013) CCRS 2012-2013 Quick Stats. http://www.cihi.ca/CIHI-ext-portal/xls/internet/CCRS_QUICKSTATS_12-13_EN Accessed 13 September 2013
20. Beck AM, Kofod J (2003) Måltidsservice på plejecentre, Status og forslag til initiative. http://www.foedevarestyrelsen.dk/Publikationer/Alle%20publikationer /2003004.pdf Accessed 14 September 2013 (in Danish)
21. American Health Care Association (2013) LTC Stats: Nursing Facility Patient Characteristics Report, June 2013 Update. http://www.ahcancal.org/research_data/oscar_data/NursingFacilityPatientCharacteristics/LTC%20STATS_HSNF_PATIENT_2013Q2_FINAL.pdf Accessed 13 September 2013
22. Japan Geriatrics Society (2012) Guideline on decision-making process in health care for the elderly. http://www.jpn-geriat-soc.or.jp/info/topics/pdf/jgs_ahn_gl_2012.pdf. Accessed 11 February 2013 (in Japanese)
23. Kosaka Y, Nakagawa-Satoh T, Ohrui T, Fujii M, Arai H, Sasaki H (2012) Survival period after tube feeding in bedridden older patients. Geriatr Gerontol Int 2012;12:317-321
24. Onishi J, Masuda Y, Kuzuya M, Ichikawa M, Hashizume M, Iguchi A. Long-term prognosis and satisfaction after percutaneous endoscopic gastrostomy in a general hospital. Nihon Ronen Igakkai Zasshi 2002;39:639-642 (in Japanese)
25. Hisano S. The relationship between Revised Hasegawa Dementia Scale (HDS-R), Mini-Mental State Examination (MMSE) and Bed-fast Scale, Dementia Scale. Japanese Journal of Geriatric Psychiatry 2009;20:883-891 (in Japanese)
26. Higaki F, Yokota O, Onishi M. Factors predictive of survival after percutaneous endoscopic gastrostomy in the elderly: is dementia really a risk factor? Am J Gastroenterol 2008;103:1011-1016
27. Shega JW, Hougham GW, Stocking CB, Cox-Hayley D, Sachs GA. Barriers to limiting the practice of feeding tube placement in advanced dementia. J Palliat Med 2003;6:885-893
28. Gadsby R. Percutaneous endoscopic gastrostomy (PEG) feeding in elderly people with diabetes resident in nursing homes. J Nutr Health Aging 2013;17:16-18
29. Sharp HM, Shega JW. Feeding tube placement in patients with advanced dementia: the beliefs and practice patterns of speech-language pathologists. Am J Speech Lang Pathol 2009;18:222-230
30. Ministry of Health, Labour and Welfare (2013) Hospital Report 2011. http://www.mhlw.go.jp/toukei/saikin/hw/iryosd/11/dl/byoin.pdf. Accessed 14 February 2013 (in Japanese)
31. OECD (2012) OECD Health Data 2012.
32. Ogita M, Utsunomiya H, Akishita M, Arai H. Indications and practice for tube feeding in Japanese geriatricians: implications of multidisciplinary team approach. Geriatr Gerontol Int 2012;12: 643-651
33. Nakanishi M, Nakashima T. Features of the Japanese national dementia strategy in comparison with international dementia policies: How should a national dementia policy interact with the public health- and social-care systems? Alzheimers Dement 2013. doi: 10.1016/j.jalz.2013.06.005
34. Aita K, Takahashi M, Miyata H, Kai I, Finucane TE.Physicians' attitudes about artificial feeding in older patients with severe cognitive impairment in Japan: a qualitative study. BMC Geriatr 2007;7:22
35. Hanson LC, Carey TS, Caprio AJ, Lee TJ, Ersek M, Garrett J, Jackman A, Gilliam R, Wessell K, Mitchell SL. Improving decision-making for feeding options in advanced dementia: a randomized, controlled trial. J Am Geriatr Soc 2011;59:2009-2016
36. Snyder EA, Caprio AJ, Wessell K, Lin FC, Hanson LC. Impact of a decision aid on surrogate decision-makers' perceptions of feeding options for patients with dementia. J Am Med Dir Assoc 2013;14:114-118
37. Monteleoni C, Clark E. Using rapid-cycle quality improvement methodology to reduce feeding tubes in patients with advanced dementia: before and after study. BMJ 2004;329:491-494
38. Hanson LC, Ersek M, Gilliam R, Carey TS. Oral feeding options for people with dementia: a systematic review. J Am Geriatr Soc 2011;59:463-472
39. Teno JM, Mitchell SL, Gozalo PL, Dosa D, Hsu A, Intrator O, Mor V. Hospital characteristics associated with feeding tube placement in nursing home residents with advanced cognitive impairment. JAMA 2010;303:544-550
40. Modi SC, Whetstone LM, Cummings DM. Influence of patient and physician characteristics on percutaneous endoscopic gastrostomy tube decision-making. J Palliat Med 2007;10:359-366
41. Lin LC, Li MH, Watson R. A survey of the reasons patients do not chose percutaneous endoscopic gastrostomy/jejunostomy (PEG/PEJ) as a route for long-term feeding. J Clin Nurs 2011;20:802-810
42. Lubart E, Leibovitz A, Habot B. Attitudes of relatives and nursing staff toward tuboenteral feeding in severely demented patients. Am J Alzheimers Dis Other Demen 2004;19:31-34