

# Feeding Tubes for Older People With Advanced Dementia Living in the Community in Israel

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Netta Bentur, PhD<sup>1</sup>, Shelley Sternberg, MD, FRCPC<sup>2,3</sup>,  
Jennifer Shuldiner, MPH<sup>1</sup>, and Tzvi Dwolatzky, MD, MBBCh<sup>4,5</sup>

## Abstract

**Background:** Feeding tubes to address eating problems of older people with advanced dementia (OPAD) has been studied primarily in nursing homes. **Objectives:** To examine the prevalence of feeding tube use among OPAD living in the community; to evaluate the characteristics, quality of care, and the burden on caregivers. **Methods:** A cross-sectional survey of 117 caregivers of OPAD living in the community. **Results:** Of 117 patients, 26% had feeding tubes. Compared to nonusers, feeding tube users had more use of restraints, greater problems with swallowing, more emergency room visits, and were more likely to have a legal guardian. In addition, caregivers of feeding tube users were older and reported very heavy burden of care. Half of the caregivers reported that the medical team consulted them before insertion of the feeding tube. **Conclusion:** Feeding tube use in OPAD in the community is associated with negative outcomes and increased caregiver burden.

## Keywords

tube feeding, quality of care, end of life, dementia, community

## Background

As the population ages, there will be a significant rise in the number of older people having dementia.<sup>1</sup> Older people with advanced dementia (OPAD) often experience eating problems, malnutrition, and recurrent infections.<sup>2</sup> Problems with eating may include food refusal, manifested by turning the head away, keeping the mouth shut, pushing the spoon away, or spitting.<sup>3</sup> These symptoms occur in almost 90% of OPAD.<sup>4</sup> Dysphagia, the most serious eating problem affecting some 70% of patients with dementia, is a swallowing problem that increases the risk of aspiration, pneumonia, malnutrition, and dehydration.<sup>5,6</sup>

Considerable controversy exists regarding the approach to dealing with serious eating and swallowing problems in OPAD. Options range from modified oral feeding using adjusted diets and specialized techniques to enteral feeding using nasogastric or percutaneous endoscopic gastrostomy (PEG) tubes. The decision to insert a feeding tube involves careful consideration of the clinical and ethical appropriateness.<sup>7-10</sup> The American Geriatrics Society recommends careful hand feeding for patients with advanced dementia. Research has shown that this form of feeding results in similar outcomes with regard to death, aspiration pneumonia, functional status, and patient comfort compared to feeding tube use.<sup>11</sup>

Many studies have described the burdens of feeding tube use and the apparent lack of benefit in OPAD.<sup>12-17</sup> In the United States, researchers led by Finucane and Gillick

have advocated strongly against the insertion of feeding tubes,<sup>7,12</sup> arguing that eating problems should be regarded as a symptom of end-stage dementia. They maintain that an invasive procedure, such as the insertion of a feeding tube, is not appropriate under these circumstances. Studies done by Mitchell and Teno on nursing home residents with advanced dementia, using Minimal Data Set (MDS) administrative data, have shown that PEG tube insertion does not prolong survival, prevent aspiration pneumonia, heal pressure ulcers, or improve quality of life.<sup>18-22</sup> However, observational Israeli studies on nursing home residents with advanced dementia have shown that PEG insertion does have beneficial effects on survival and aspiration prevention.<sup>23,24</sup>

<sup>1</sup> Aging Department, Myers-JDC-Brookdale Institute, Jerusalem, Israel

<sup>2</sup> Division of Public Health, Maccabi Healthcare Services, Jerusalem, Israel

<sup>3</sup> Aging Department, Shaarei Zedek Medical Center Memory Clinic, Jerusalem, Israel

<sup>4</sup> Faculty of Health Sciences, Mental Health Center, and Center for Multidisciplinary Research in Aging, Ben-Gurion University of the Negev, Beersheva, Israel

<sup>5</sup> Aging Department, Rambam Health Care Campus, Haifa, Israel

## Corresponding Author:

Netta Bentur, PhD, Aging Department, Myers-JDC-Brookdale Institute, JDC Hill, POB 3886, Jerusalem 91037, Israel.

Email: bentur@jdc.org.il

Despite research evidence to the contrary, PEG insertion remains commonplace in the United States for OPAD. In a national MDS study of nursing homes in the United States, the prevalence of feeding tubes was reported as 18% for OPAD.<sup>25</sup> An Italian chart review reported a feeding tube prevalence rate of 21% in 6 large nursing homes among OPAD.<sup>26</sup> In a chart review comparing Canada and Israel, the reported prevalence of feeding tubes in advanced dementia was 5% in non-Jewish nursing homes and 20% in Jewish nursing homes in Canada, compared to 53% in Israeli nursing homes.<sup>27</sup> This higher prevalence rate of feeding tube use for OPAD in Israel can be explained in part by the centrality of the principle of the sanctity of human life in traditional Jewish thinking.<sup>28,29</sup> For cultural, historical, and ethical reasons, it is posited that Israel as a society sees food and fluid as a basic necessity of life rather than a medical intervention in end-of-life care. This is reflected in the 2005 Israeli Dying Patient act in which the request to withhold food and fluid cannot be proscribed until the person is in a terminal stage defined as having 2 weeks to live.<sup>30-32</sup>

In addition to cultural factors, Israel has a higher proportion of individuals with dementia who live in the community compared to many other countries. According to a 2002 Israeli national survey, 84% of people with dementia were living in the community.<sup>33</sup> In the United Kingdom, 67% of people with dementia live in the community,<sup>34</sup> and in the United States, 60% to 70% of people with dementia live in the community.<sup>1</sup> There are no published data on the percentage of those living in the community who have advanced dementia. However, Mitchell et al<sup>35</sup> stated that the majority (67%) of dementia-related deaths in the United States occurred in nursing homes, indicating that most individuals with dementia are cared for in nursing homes at the end of life.

Given the increasing prevalence of dementia and the very limited data on the prevalence of feeding tube use in OPAD living in the community, our study was designed with the following aims: (1) examine the prevalence of feeding tube use among OPAD living in the community in Israel, (2) describe the demographic, social, and medical characteristics of OPAD and to compare feeding tube users and nonusers, and (3) describe the quality of care of OPAD and the burden of care on their caregivers, and to compare feeding tube users and nonusers.

## Methods

### Study Population

Interviews were conducted with 117 family caregivers of OPAD living in the community. Of the 117 family caregivers, 65 (56%) were currently taking care of an OPAD, and 52 (44%) had recently been bereaved (in the 3–6 months prior to the interview) of an OPAD. Advanced dementia was defined as stages 6 to 7 of the Global Deterioration Scale, a 7-point scale used to indicate the severity of a primary degenerative dementia.<sup>36</sup> All the OPAD were members of Maccabi Healthcare Services (MHS), the second largest Preferred-Provider Organization in

Israel. Maccabi Healthcare Services has a nationwide network of over 3000 physicians providing health care services to 1.8 million members (24% of the country's population) in Israel. This study was confined to the 3 largest regions of MHS.

We defined "family caregiver" as the person who resided with the OPAD, provided most of the care without payment, and was primarily responsible for the coordination of services and maintaining contact with the health care system.

The sample of OPAD and their family caregivers was identified in last 3 months of 2012 from the MHS administrative database, and from participants in home care programs in 3 districts participating in the study. Of the 156 people who were identified, caregivers were enrolled consecutively and interviews were conducted with 75% (117) of the caregivers. Interviews were not conducted for the following reasons: refusal (13%), geographical distance (3%), and other reasons (9%).

### Data Collection

A MHS nurse contacted the responsible physician to verify the diagnosis of advanced dementia and confirmed that the older person was living in the community or had lived in the community during the last 3 months of life. The nurse then phoned the family caregiver, explained the study objectives and requested consent for an interview. Names of consenting family members were passed on to the study interviewers. A face-to-face interview was conducted in the caregiver's home in either Hebrew, Russian, or English using a closed structured questionnaire. Written informed consent was obtained from all participants prior to the interview. The study was approved by the ethics committee of MHS.

### The Study Variables

The primary outcome of this study was the use of a feeding tube (PEG or nasogastric) among OPAD. This was determined by asking the family caregiver "During the advanced stages of the disease was a PEG inserted?" and "During the advanced stages of the disease was a nasogastric tube inserted?"

Data collected regarding the OPAD included demographic characteristics (gender, education, and religious observance), comorbidities, medications, the appointment of a power of attorney or legal guardian, and the use of health care services (such as home care and the number of visits to the emergency room over the last year).

The quality of end-of-life care and satisfaction with care in dementia were measured by interviewing the caregivers using 3 specifically constructed advanced dementia end-of-life scales: symptom management end-of-life in dementia (SM-EOLD), comfort assessment in dying end-of-life in dementia (CAD-EOLD), and satisfaction with end-of-life care end-of-life in dementia (SWC-EOLD) scales.<sup>37</sup> The symptom management scale measures symptoms that occurred during the last 90 days of the illness or dying process, with higher scores representing better symptom management. The comfort assessment in dying instrument measures symptoms commonly observed during the

dying process, with higher scores representing greater comfort. For the satisfaction with end-of-life care scale, higher scores indicate greater satisfaction.

Data collected concerning family caregivers included demographic characteristics (gender, education, and religious observance); whether a family member was involved in the decision-making process to insert a feeding tube; the burden of making decisions (“How much of a burden was it to make end of life decisions regarding the older person when he/she was not able?”); and the burden of care (“In general, the burden you feel from acting as a caregiver can be described as . . .”). Depression was assessed using the Agency for Healthcare Research and Quality 2-question validated screening tool for depression.<sup>38</sup>

### Data Analysis

The data were analyzed using SPSS 21 software for Windows. Descriptive statistics (mean and standard deviation for continuous variables and frequency for categorical variables) were used to describe the prevalence of feeding tube use. Bivariate analysis was performed to compare the characteristics feeding tube users and nonusers and the impact of feeding tube on their quality of life and on family caregiver burden.

## Results

### Prevalence of Feeding Tubes

Of the 117 OPAD, 30 (26%) had feeding tubes—15 (13%) with PEG and 15 (13%) with nasogastric tubes. When comparing those with PEG to those with nasogastric tubes, PEG use was more frequent among Ultra-Orthodox and traditional Jewish families compared to secular ones (7 of the 15 PEG users were Ultra-Orthodox or traditional Jews compared to 2 of the 15 nasogastric tube users), PEG caused more diarrhea (6 of the 15 PEG users had diarrhea compared to 1 of the 15 nasogastric tube users), and was associated with less use of restraints (1 of the 15 PEG users compared to 9 of the 15 nasogastric users).

### Characteristics of the OPAD

About two-thirds (67%) of the 117 OPAD were females. The mean age at the time of death or interview was  $86.6 \pm 7.6$  years, and patients had an average educational level of  $10.7 \pm 5.5$  years. There were no significant demographic differences between feeding tube users and nonusers. The OPAD had an average of  $4.4 \pm 2.3$  diseases, 36% had pressure sores, 30% had frequent diarrhea, 58% received medication for control of behavioral disturbances, 16% used restraints, 66% had problems swallowing, 62% took food supplements such as nutritional formulas, 50% had weight problems, and 24% had fallen at least once during the advanced stage of the disease. Although there was not a significant difference in the average number of diseases between feeding tube users and nonusers, a statistically significant greater proportion of those with feeding tubes had a stroke (50% vs 28%,  $P < .05$ ). Additionally, feeding tube users as compared to nonusers had a statistically

**Table 1.** Demographic Characteristics of Feeding Tube Nonusers and Users.

Variables	Feeding Tube Usage		All, N = 117
	Feeding Tube Nonusers, N = 87	Feeding Tube Users, N = 30	
Gender			
Female	66.7%	63.3%	65.7%
Age, years			
0-74	8.9%	3.3%	7.2%
75-84	25.3%	30.0%	47.0%
85-94	45.6%	60.0%	48.6%
95+	20.3%	6.7%	17.1%
Mean	$86.33 \pm 8.20$	$86.37 \pm 5.59$	$86.5 \pm 7.7$
Education			
More than high school	29.9%	20.0%	26.6%
Place of birth			
Not in Israel	89.7%	92.3%	90.6%
Religiosity			
Ultra-Orthodox/ Orthodox	27.8%	30.0%	27.9%
Traditional	29.1%	20.0%	26.1%
Secular	43.0%	50.0%	45.9%

significant ( $P < .05$ ) greater use of restraints (35% vs 10%), more problems swallowing (90% vs 58%), and took more food supplements (77% vs 57%).

Health service utilization assessment revealed that 77% of OPAD were under the care of the home care program, 36% had visited the emergency room in the previous year during the day, and 29% during the night. More feeding tube users than nonusers had visited the emergency room at least once during the day (40% vs 34%,  $P < .05$ ). In addition, feeding tube users had a higher number of emergency room visits on average in the previous year than that of the nonusers ( $2.92 \pm 1.68$  times compared to  $1.6 \pm 0.9$  during the day and  $2.9 \pm 1.6$  times compared to  $1.4 \pm 0.5$  times at night,  $P < .05$ ).

Of the 52 OPAD who had died prior to the interview, 80% died in a hospital, 10% in a nursing home, and 10% at home. Although the difference between feeding tube users and nonusers was not significant, it is interesting to note that only 10% of feeding tube users died at home compared to 32% of nonusers (Table 1).

About 38% of OPAD had a legal guardian and 22% had a power of attorney. More people had a legal guardian among feeding tube users (55%) compared to nonusers (33%,  $P < .05$ ; Table 2).

### Quality of Care

The mean score on the SM-EOLD scale of the 117 OPAD was  $28.7 \pm 10.0$  (Table 3). Although not significant, poorer CAD-EOLD was found among feeding tube users compared to nonusers. A statistically significant difference was found in the

**Table 2.** Health and Health Care Service Utilization Among Feeding Tube Users and Nonusers.<sup>a</sup>

Variables	Feeding Tube Usage		All, N = 117
	Feeding Tube Nonusers, N = 87	Feeding Tube Users, N = 30	
Comorbidity			
Number of diseases	4.4 ± 2.2	4.4 ± 3.3	4.4 ± 2.2
Pressure ulcers	34.2	37.9	35.2
Diarrhea	32.5	24.1	30.0
Took medication to relax	60.5	50.0	57.7
Had restraints <sup>b</sup>	9.9	34.5	16.4
Problem swallowing <sup>b</sup>	58.0	89.7	66.4
Took food supplements <sup>b</sup>	56.8	76.7	62.2
Weight problems	50.6	48.3	50.0
Falls	53.8	43.3	50.9
Was in the home care program	79.7	75.9	76.8
Went to the emergency room in the previous year			
Went to the ER at night	22.7	48.1	29.4
Went to the ER during the day <sup>b</sup>	34.2	40.0	35.8
Number of times during the night <sup>b</sup>	1.6 ± 0.9	2.9 ± 1.7	2.0 ± 1.3
Number of times during the day <sup>b</sup>	1.4 ± 0.5	3.0 ± 1.6	2.2 ± 1.4
Had a legal guardian <sup>b</sup>	32.9	55.2	38.2
Had a power of attorney	21.5	24.1	21.8
Place of death, N = 52			
House	32.1	10.0	44.0
Nursing home/hospital	67.9	90.0	66.0

Abbreviation: ER, emergency room.

<sup>a</sup>All values are % unless otherwise stated.<sup>b</sup>*P* < .05.**Table 3.** End-of-Life Care Among Feeding Tube Users and Nonusers.

Variables	Feeding Tube Usage		All, N = 117
	Feeding Tube Nonusers, N = 87	Feeding Tube Users, N = 30	
Symptom management (SM-EOLD)	28.9 ± 9.4	28.1 ± 11.8	28.7 ± 10.0
psychological symptoms	18.8 ± 7.5	17.5 ± 8.1	18.5 ± 7.6
physical symptoms	8.6 ± 4.3	7.1 ± 3.6	8.2 ± 4.2
Care assessment in dying (CAD-EOLD)	32.2 ± 7.1	28.9 ± 5.7	31.0 ± 6.8
Physical distress	8.8 ± 2.6	7.42 ± 2.6	8.3 ± 2.6
Dying symptoms	9.2 ± 2.3	9.25 ± 0.9	9.2 ± 1.9
Emotional symptoms	10.0 ± 2.3	9.58 ± 2.7	9.9 ± 2.4
Well-being <sup>a</sup>	6.9 ± 2.3	5.20 ± 2.0	6.3 ± 2.3

Abbreviations: SM-EOLD, symptom management end-of-life in dementia; CAD-EOLD, care assessment in dying end-of-life in dementia.

<sup>a</sup>*P* < .05.

well-being subscale of the CAD-EOLD between feeding tube users and nonusers ( $5.20 \pm 2.0$  vs  $6.92 \pm 2.3$ ,  $P < .05$ ). No difference was found between OPAD with a PEG and OPAD with a nasogastric tube regarding SM-EOLD ( $31.3 \pm 12.9$  vs  $25.5 \pm 10.6$ , respectively) and the CAD-EOLD ( $29.5 \pm 5.7$  vs  $28.5 \pm 6.0$ , respectively).

### Family Caregiver Burden

Caregivers had an average age of  $62 \pm 12$  years with the majority (73%) being female. Most (74%) of the family caregivers were children of the OPAD while 22% were spouses. The average educational level of family caregivers was 14.8

$\pm 4.4$  years, 68% were born outside of Israel and 50% were secular Jews (Table 4). Caregivers of OPAD with feeding tubes were older ( $60 \pm 12$  vs  $66 \pm 13$  years,  $P < .05$ ) when compared to feeding tube nonusers.

Half of the caregivers reported that the medical team consulted them before insertion of the feeding tube (67% among PEG and 28% among nasogastric). Regarding who made the decision, half of the caregivers reported that they or another family member had made the decision for feeding tube insertion, 20% reported that the medical staff had decided, 20% reported that the decision was made by family members with the medical staff, and 10% did not know who had made the decision (Table 5).

**Table 4.** Demographic Characteristics of Caregivers of Feeding Tube Users and Nonusers.

Variables	Feeding Tube Usage		All, N = 117
	Feeding Tube Nonusers, N = 87	Feeding Tube Users, N = 30	
Gender			
Female	26.2%	30.0%	27.3%
Age <sup>a</sup>	60.1 ± 11.9	65.9 ± 13.3	61.7 ± 12.5
Education			
More than high school	68.4%	66.7%	67.6%
Relationship to patient			
Spouse	19.0%	31.0%	22.7%
Other	81.0%	69.0%	77.3%
Place of birth			
Not in Israel	63.3%	79.3%	68.2%
Religiosity			
Ultra-Orthodox/Orthodox	27.3%	30.8%	27.6%
Traditional	26.0%	11.5%	21.9%
Secular	46.8%	57.7%	50.5%

<sup>a</sup>P < .05.**Table 5.** Satisfaction and Quality of Care Variables of Caregivers of Feeding Tube Users and Nonusers.

Variables	Feeding Tube Usage		All, N = 117
	Feeding Tube Nonusers, N = 87	Feeding Tube Users, N = 30	
Satisfaction with care (SWC-EOLD)	32.0 ± 9.38	31.7 ± 11.75	31.9 ± 6.7
Physician knew enough to treat properly			
Knew so so/not so much	27.1%	24.1%	26.7
Knew well/very well	72.9%	75.9%	73.3
Perceived burden of care <sup>a</sup>			
Very heavy	19.2%	44.8%	27.2
Heavy	54.8%	31.0%	44.6
Not so heavy/not at all heavy	26.0%	24.1%	25.2
Depression			
Not depressed	42.5%	48.3%	43.0
Possible depression	57.5%	51.7%	57.0
Felt able to care for patient			
Not at all/not so much	10.8%	3.8%	8.8
A lot	37.8%	34.6%	37.3
Completely	51.4%	61.5%	53.9
How hard decisions were at the end of life			
Very hard	27.0%	36.7%	31.1
Medium hard	23.0%	23.3%	22.6
A little hard/not hard	50.0%	40.0%	46.2

Abbreviation: SWC-EOLD, satisfaction with care end-of-life in dementia

<sup>a</sup>P < .05.

The mean SWC-EOLD score as reported by the 117 family caregivers was 31.9 ± 6.7, with no difference between family caregivers of feeding tube users and nonusers. No difference was found between OPAD with a PEG and OPAD with a nasogastric tube regarding the SWC-EOLD (32.3 ± 6.3 vs 31.1 ± 6.8, respectively). About 73% of caregivers reported that the physician knew either very well or well how to care for the OPAD, with no difference between feeding tube users and nonusers. In response to a question about overall burden of care for the OPAD, 75% reported it to be “heavy” or “very heavy.” Additionally, about 57% of caregivers screened positive for

possible depression. About 44% of those caring for OPAD who were feeding tube users reported very heavy burden compared to 19% of those caring for OPAD who were feeding tube nonusers (*P* < .05).

## Discussion

We found that more than a quarter of OPAD living in the community had either a nasogastric or a PEG feeding tube. Compared to nonusers, feeding tube users had more use of restraints, greater problems swallowing, a lower well-being

score (a subscale of the CAD-EOLD), more emergency room visits, and were more likely to have a legal guardian. In addition, caregivers of feeding tube users were older and reported greater burden of care.

The prevalence of feeding tube use in this study was lower than that reported in a study of Israeli nursing homes.<sup>27</sup> However, the prevalence in our study was higher than rates reported in the United States and Italy. In the United States, the national prevalence of feeding tubes in nursing homes was reported to be 18%,<sup>25</sup> while the prevalence in all institutions (hospital, nursing homes, and assisted living) was reported to be 10%.<sup>19</sup> In Italy, a study of 7 long-term care institutions reported a prevalence of 21%.<sup>26</sup> Few studies address feeding tube use in community dwelling OPAD. We identified 1 US study that reported a 12% prevalence of feeding tube use in home care patients<sup>39</sup> compared to our prevalence of 26%.

Our study did not find any statistically significant differences between demographic characteristics of feeding tube users and nonusers. Our findings are not consistent with the literature that has found feeding tubes to be used less commonly in older patients, based on the tendency to withhold some medical interventions at the end of life.<sup>40</sup> Either the age of our study sample was too homogenous to find a difference or our finding reflects a determination to continue medical intervention regardless of age.

Our study reports a higher prevalence of restraint use than reported by others (35% vs 26%<sup>19</sup>). We found that feeding tube users were 3 times more likely than nonusers to be restrained. Another study<sup>41</sup> also reported that feeding tube use was associated with restraints. However, it is difficult to determine from our study whether the use of restraints was a direct consequence of having a feeding tube. Feeding tubes may cause agitation leading to the use of physical or chemical restraints to avoid self-harm,<sup>42</sup> and this may be seen as a violation of patients' dignity. The risk of restraints should be part of the conversation of benefits and potential risks of feeding tube insertion.

Our findings suggest that the presence of a power of attorney was associated with feeding tube use. In contrast, 2 studies in the United States reported that the absence of a power attorney was associated with feeding tube use.<sup>18,43</sup> This is understandable since in Israel, the insertion of a PEG requires that the caregiver obtain power of attorney. Additionally, it may explain the high rate of OPAD with a nasogastric tube among feeding tube users (52%) since this procedure does not require the physician to obtain power of attorney from the caregiver.

When considering the impact of feeding tube use on quality of care, no significant difference was found between feeding tube users and nonusers in the total scores of SM-EOLD and CAD-EOLD. We did find a significant difference favoring better quality of care among feeding tube nonusers in the well-being subscale of the care assessment in dying scale (CAD-EOLD). Respondents whose loved ones died with a feeding tube, as reported by Teno et al,<sup>19</sup> were also less likely to report excellent end-of-life care.

Only half of the caregivers reported that the insertion of a feeding tube was discussed with the caregiver by medical

personnel before insertion (67% among PEG and 28% among nasogastric) and one-fifth reported that the medical staff had decided whether to insert a feeding tube. This finding highlights the fact that communication regarding feeding tube insertion was not optimal. Rates of reported discussion were greater in studies from the United States, ranging from 71% to 90%.<sup>21,44,45</sup> Finally, caregivers of OPAD who were feeding tube users reported more burden compared to caregivers of OPAD who were feeding tube nonusers.

The strengths of our study are that it contributes to the limited literature on characteristics of OPAD living in the community with feeding tubes. In addition, our face-to-face interview facilitated completeness of data. However, the study has several limitations. First, recall bias cannot be ruled out for bereaved caregivers. We made an effort to limit this bias by minimizing the time between the death of the OPAD and the performance of the caregiver interview. Second, information regarding the medical variables such as the number of comorbidities and medications, and swallowing problems, were based on caregiver reports. Finally, our relatively small sample size did not enable us to conduct a meaningful multivariate analysis of the data.

Our study reported that the prevalence of feeding tube use in a cohort of OPAD living in the community was 26%. Additionally, only half of the caregivers reported that the insertion of a feeding tube was discussed with medical personnel. Feeding tube users had more restraints, problems swallowing, emergency room visits, a lower well-being score (a subscale of the CAD-EOLD), and had legal guardians. Their caregivers reported more burden of care. Future studies should investigate the effect of feeding tube use longitudinally.

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