

Dement Geriatr Cogn Disord Extra 2018;8:268-276

DOI: 10.1159/000489489 Received: March 20, 2018 Accepted: April 20, 2018 Published online: July 20, 2018 © 2018 The Author(s) Published by S. Karger AG, Basel www.karger.com/dee



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Original Research Article

Doctors' Knowledge and Attitudes Regarding Enteral Feeding and Eating Problems in Advanced Dementia

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Keywords

Advanced dementia · Eating problems · Feeding tube · Doctor's attitudes

Abstract

Background: The use of feeding tubes (FTs) in patients with advanced dementia does not yield positive health outcomes and can have a negative effect. **Methods:** A cross-sectional study assessed the knowledge and attitudes of physicians on the use of FTs for patients with advanced dementia. **Results:** 201 of 240 doctors (83.8%) participated in the study; 61.7% of the doctors claimed that FTs prevent aspiration, 51.7% that they prevent pneumonia, and 38.8% that they prevent weight gain. Almost one-third (32.3%) said that the decision to use FTs could be taken by a hospitalist or a primary physician (28.9%). **Conclusion:** We found large gaps in knowledge among doctors about the use of FTs and consequences in patients with advanced dementia.

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Introduction

Eating problems are a common manifestation of dementia. The prevalence of eating disorders in advanced dementia ranges from 13 to 86% [1–3] and increases as the disease progresses [4–6]. Eating problems in advanced dementia are associated with an increased risk of pneumonia [7, 8], high fever and hospitalization [1], apathy and hallucinations [9], and high mortality rates [1, 3, 5, 7, 10]. To manage eating problems in patients with advanced dementia,

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DOI: 10.1159/000489489

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medical teams often use enteral feeding by means of a feeding tube (FT) in the form of nasogastric tubes (NGT) or a percutaneous endoscopic gastrostomy (PEG). The rate of use of FTs is in the range of 4.7–20.5% in the USA and Canada [11, 12] and 26–53% in Israel [13, 14].

The medical literature on using FTs for patients with advanced dementia raises important issues. Feeding by FT does not improve patients' physical condition, functional status, or cognitive function [15, 16] and is associated with an increased incidence of aspiration [17]. It does not reduce (and can even increase) the risk of pneumonia [18], improve patients' quality of life [18] or malnutrition status [19], or prevent pressure sores (or promote their healing) [20]. It does not affect the survival rate [21–26] and may even lead to increased mortality [27, 28]. The use of FTs in patients with advanced dementia can cause adverse effects including diarrhea [29], tube-related problems such as leaks and obstructions [18–20], an increased need for restraints, and an increased burden on caregivers [13, 30].

There is a general consensus among professional organizations against recommending the use of FTs in patients with advanced dementia; this is based on the results of studies and the opinion of experts in the field, with a high grade of evidence and a strong strength of recommendation [31–34]. Despite these recommendations, there has been an increase in the rate of use of FTs in patients with advanced dementia, that stems, among other factors, from the attitudes of the medical team [35] and gaps in doctors' knowledge about FTs [36]. This study assessed the knowledge and attitudes of doctors, who treat elderly patients, about the use of enteral feeding among patients with advanced dementia.

Materials and Methods

This was a cross-sectional study involving doctors who worked in 2 settings:

- 1. Doctors in the primary care clinics of the Clalit Healthcare Services in the city of Beer-Sheva (approx. 130 doctors). Beer-Sheva is a city in southern Israel with a population of >200,000 residents, 65% of whom are insured by the Clalit Healthcare Services.
- 2. Doctors who work in the Division of Internal Medicine in the Soroka University Medical Center in Beer-Sheva (approx. 110 doctors). This medical care center serves >1 million residents in the southern region of Israel.

A self-administered study questionnaire was developed. It was anonymous and included questions on sociodemographics, knowledge, and attitudes regarding eating disorders in patients with advanced dementia. The questionnaire was handed out to the participating doctors between November 2016 and April 2017 at staff meetings in different settings, i.e., the Internal Medicine wards, the emergency room, primary care clinics in the community, and the Department of Family Medicine at the Ben-Gurion University of the Negev.

The sample size of 200 doctors was calculated based on the results of a previous study [37] in which 25–40% of the doctors had sufficient knowledge about the use of FTs. The category "sufficient knowledge" included doctors who answered "No" to the question "Is it recommended to use FTs in the case of patients with advanced dementia?".

The study received an exemption from the Helsinki Committees of the Meir Medical Center and the Soroka University Medical Center.

Statistical Analysis

Descriptive analyses were conducted by frequency distribution for the categorical variables and means \pm standard deviation for continuous variables related to FT and for comparison between board-certified doctors and residents. Comparisons were also conducted between hospital-based and community-based doctors. The χ^2 test was used to compare categorical variables. Statistical significance was set at p < 0.05 throughout.





Table 1. Characteristics of the study population (n = 201)

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Age, years	
Mean ± SD	41.1±10.7
Range	28-68
Sex	
Male	105 (52.2)
Female	96 (46.8)
Country/region of birth	
Eastern Europe	92 (50.3)
Israel	80 (43.7)
Western Europe	2 (1.1)
USA and Canada	4 (2.2)
South America	5 (2.7)
Country/region of medical studies	,
Eastern Europe	93 (52.2)
Israel	72 (40.4)
Western Europe	8 (4.5)
US and Canada	1 (0.6)
South America	4 (2.2)
Country of residency training	()
Israel	169 (91.4)
Other	16 (8.6)
Specialization	,
Internal medicine	73 (36.3)
Family medicine	122 (60.7)
Professional status	
Board-certified in internal medicine	38 (18.9)
Board-certified in family medicine	49 (24.4)
Board-certified in rehabilitation medicine	2 (1.0)
Board-certified in neurology	1 (0.5)
Resident in internal medicine	33 (16.4)
Resident in family medicine	74 (36.8)
General practitioner	4 (2.0)
Work setting	
A hospital	89 (44.3)
A primary care clinic in the community	112 (55.7)
Professional seniority, years	
Mean ± SD	11.3±11.2
Range	1-41

Values express n (%), unless stated otherwise.

Results

In all, 201 doctors (83.8%) completed the study questionnaire; 89/110 doctors were hospital-based (80.9%) and 112/130 were community-based (86.1%). The mean age was 41.1 ± 10.7 years and 105 (52.2%) were male. The mean seniority was 11.3 ± 11.2 years. Forty-nine doctors (24.4%) were board-certified in family medicine, and 38 (18.9%) in internal medicine. The sociodemographic characteristics of the participating doctors are presented in Table 1.

In answer to the questions related to indications for the use of FTs (Table 2), 124 doctors (61.7%) claimed that FTs were meant to prevent aspiration, 51.7% that they prevent aspiration pneumonia, 38.8% that they prevent weight loss, 26.9% that they prolong life, 26.4% that they improve quality of life, and 21.4% that they prevent pressure sores. Only 36 doctors (17.9%) showed "sufficient knowledge" by answering "No" to the question on indications for the use of FTs in patients with advanced dementia. Community-based doctors were more



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Table 2. Comparisons of level of knowledge, by work setting and professional status

Variable	All doctors	Hospital- based doctors	Community- based doctors	p value	Board- certified	Residents	p value
N	201	89	112		90	111	
Knowledge of indications for FT use in patients with	advanced demen	tia? (>1 choice possib	le)				
Prevents aspiration	124 (61.7)	49 (55.1)	75 (67)	0.108	46 (51.1)	78 (70.3)	0.006
Prevents aspiration pneumonia	104 (51.7)	11 (12.4)	32 (28.6)	0.006	13 (14.4)	30 (27)	0.038
Prevents weight loss	78 (38.8)	38 (42.7)	66 (58.9)	0.024	44 (48.9)	60 (54.1)	0.481
Prolongs life	54 (26.9)	22 (24.7)	32 (28.6)	0.631	18 (20)	36 (32.4)	0.056
Improves quality of life	53 (26.4)	24 (27)	29 (25.9)	0.873	20 (22.2)	33 (29.7)	0.262
Prevents pressure sores	43 (21)	22 (24.5)	34 (30.4)	0.430	26 (28.9)	30 (27)	0.874
There are no indications for FT	36 (17.9)	14 (15.7)	22 (19.6)	0.579	18 (20)	18 (16.2)	0.580
Who should decide on the use of FTs? (>1 choice poss	rible)						
The patient by means of advanced medical direc-							
tives	149 (74.1)	64 (71.9)	84 (75)	0.627	60 (66.7)	89 (80.2)	0.036
The patient's family	49 (24.4)	17 (19.1)	32 (28.6)	0.138	27 (30)	22 (19.9)	0.102
The guardian	133 (66.2)	54 (60.7)	79 (70.5)	0.177	61 (67.8)	72 (64.9)	0.765
The primary physician	58 (28.9)	21 (23.6)	37 (33)	0.160	32 (35.6)	26 (23.4)	0.063
The emergency-room or ward doctor	65 (32.3)	29 (32.6)	36 (32.1)	1.000	24 (26.7)	41 (36.9)	0.132
A social worker	11 (5)	3 (3.4)	8 (7.1)	0.352	5 (5.6)	6 (5.4)	1.000
A judge	27 (13.4)	6 (6.7)	21 (18.8)	0.013	14 (15.6)	13 (11.7)	0.533
What potential complications occur with FT use? (>1	choice possible)						
Gastrointestinal bleeding	128 (63.7)	53 (59.6)	75 (67)	0.303	60 (66.7)	68 (61.3)	0.463
Patient agitation	93 (46.3)	41 (46.1)	52 (46.4)	1.000	43 (47.8)	50 (45)	0.776
Perforation	136 (67.7)	55 (61.8)	81 (72.3)	0.130	65 (72.2)	71 (64)	0.288
Diarrhea	57 (28.4)	23 (25.8)	34 (30.4)	0.530	33 (36.3)	24 (21.6)	0.027
New pressure sores in the area of the PEG or NGT	106 (52.7)	44 (49.4)	62 (55.4)	0.477	55 (61.1)	51 (45.6)	0.034
Increased burden on the primary caregiver	60 (29.9)	25 (28.1)	35 (31.3)	0.645	29 (32.2)	31 (27.9)	0.538
There are usually no complications	25 (12.4)	10 (11.2)	15 (13.4)	0.674	8 (8.9)	17 (15.3)	0.201

Values express n (%). FT, feeding tube; PEG, percutaneous endoscopic gastrostomy; NGT, nasogastric tube.

likely than hospital-based doctors to think that the use of FTs prevents pneumonia (28.6 vs. 12.4%, p = 0.006) and weight loss (58.9 vs. 42.7%, p = 0.024). Residents were more likely than board-certified doctors to answer that indications for the use of FTs include the prevention of aspiration (70.3 vs. 51.1%, p = 0.006) and pneumonia (27.0 vs. 14.4%, p = 0.038).

In terms of decision-making, 149 doctors (74.1%) thought that the decision to use FTs should be made by the patients themselves within the framework of advanced medical directives, and 133 (66.2%) thought it should be made by a legal guardian. However, close to one-third of the doctors (32.3%) thought that the decision could also be made by an emergency-room or hospital-ward doctor, primary physician (28.9%), or family member (24.4%). Furthermore, 13.3% believed that the decision should be taken by a judge or social worker (5%). Compared to hospital-based doctors, more community-based doctors thought that a judge should decide on the use of an FT (18.8 vs. 6.7%, p = 0.013). Board-certified doctors were more likely than residents to say that the decision should be made by the patients themselves within the framework of advanced medical directives (80.2 vs. 66.7%, p = 0.036).

The doctors cited the following potential complications with the use of FTs: perforation (67.7%), gastrointestinal tract bleeding (63.7%), the appearance of new pressure sores in the area of the FT (52.7%), and agitation (46.3%). Some doctors thought that there are no complications associated with the use of FTs (12.4%). Board-certified doctors were more knowledgeable than residents as to the potential complications of FTs including diarrhea (36.3 vs. 21.6%, p = 0.027) or new pressure sores (61.1 vs. 45.0%. p = 0.034). There were no significant



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Table 3. Comparisons of doctors' personal preferences, by work setting and professional status

Variable	All doctors	Hospital-based doctors	Community-based doctors	p value	Board- certified	Residents	p value
N	201	89	112		90	111	
How do you feel about having an FT should you su	ıffer from advance	d dementia yourself:	,				
I'd prefer not to have an FT to prolong life							
or prevent suffering	139 (69.2)	62 (69.7)	77 (68.8)	0.82	79 (76.7)	70 (63.1)	0.166
I'd prefer to have an FT	17 (8.5)	9 (10.1)	8 (7.1)		6 (6.7)	11 (9.9)	
I'd prefer that my family make that decision							
should the time come	14 (7)	6 (6.7)	8 (7.1)		6 (6.7)	8 (7.2)	
I'd let the medical team make that decision	31 (15.4)	12 (13.5)	19 (17)		9 (10)	22 (19.8)	
Which factors would affect your decision about ha	ıving an FT? (>1 cl	noice possible)					
Religion and faith	71 (35.3)	27 (30.3)	44 (39.3)	0.235	26 (28.9)	45 (40.5)	0.103
My country of origin	12 (6)	4 (4.5)	8 (7.1)	0.554	5 (5.6)	7 (6.3)	1.000
Cultural considerations	43 (16.9)	8 (9)	26 (23.2)	0.008	20 (22.2)	14 (12.6)	0.089
Family considerations	59 (29.4)	26 (29.2)	33 (29.5)	1.000	31 (34.4)	28 (25.2)	0.164
My medical education	102 (50.7)	46 (51.7)	56 (50)	0.887	41 (45.6)	61 (55)	0.204
Legal considerations	72 (35.8)	31 (34.8)	41 (36.6)	0.882	30 (33.3)	42 (37.8)	0.556

differences in the level of knowledge about potential complications between the hospital-based and community-based doctors.

The doctors were asked about their preferences relating to insertion of a FT if they themselves suffered from advanced dementia (Table 3). One hundred and thirty-nine doctors (69.2%) answered that they would not agree to FT insertion if they suffered from advanced dementia with eating problems. Only 8.5% stated that they would prefer to be treated with an FT. Only 7% would like that their close family members reach the decision, and 15.4% would agree that the medical team decide. In comparison to the other doctors, fewer of the 36 with sufficient knowledge would prefer to have an FT inserted in a similar situation (2.8 vs. 9.7%) or that the medical team reach the decision for them (11.1 vs. 16.4%).

When asked about the factors that affect the decision on the use of FTs, 50.7% said that the medical education that they had received would affect their decision as to whether to have an FT if they suffered from advanced dementia. Smaller percentages of doctors cited legal considerations (35.8%), religion and faith (35.3%), or family considerations (29.4%) as factors that could influence their personal decision. They were no significant differences on these issues between hospital-based or community-based doctors or between board-certified doctors and residents.

Discussion

In this study, we evaluated doctors' knowledge and attitudes towards enteral feeding of patients with advanced dementia and eating problems. We found significant gaps in knowledge among the doctors about the indications for FTs, with only 36 doctors (17.9%) answering that there is in fact no indication for the use of FTs in these patients (based on recommendations in the medical literature [31, 34]).

The widespread use of FTs in patients with advanced dementia has been reported previously in the literature, and possible reasons for FT use include the lack of a preparatory discussion with family members [13, 38], religious and/or cultural considerations [39, 40],



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legal considerations [41], the attitudes of the medical team [35], a lack of medical team knowledge [36], or unrealistic expectations on the part of doctors [14, 37, 38, 42].

Compared to the study by Teno et al. [36], we did not find significant gaps in knowledge or differences in attitudes between hospital-based and community-based doctors, with one exception, i.e., that significantly more community-based doctors thought that the use of FTs would prevent weight loss and pneumonia. The comparison between board-certified doctors and residents also did not show significant differences in knowledge and attitudes in favor of the more senior doctors, with the exception of a few isolated parameters.

A high percentage of participating doctors thought that doctors, social workers, and judges should be responsible for the decision about the use of FTs. This finding is of concern, as it could explain the widespread use of FTs and is consistent with previous reports that the use of FTs is primarily based on the decisions made by doctors without involving the patient or their family [13, 35, 38, 43]. We found that board-certified doctors, compared to residents, were less likely to think that the decision should be reached by the patients within the framework of advanced medical directives (66.7 vs. 80.2%, p = 0.036). It is not clear if this finding can be explained by the assumption that younger doctors are less paternalistic and more likely to give autonomy to their patients, or that more senior doctors are more influenced by their ongoing clinical experience.

In the past, a gap was reported between the exaggerated expectations of doctors about the use of FT and their own personal preferences [37]. In a study by Carmel [44] that evaluated differences in attitudes between doctors and patients on the use of FTs in irreversible severe physical conditions and irreversible mental illness, for both conditions the doctors were more likely to recommend the use of FTs for patients than for themselves. Our findings present a similar picture. Irrespective of the level of knowledge (senior doctors vs. residents) or the work setting (i.e., hospital-based vs. community-based doctors), over two-thirds of the doctors in our study were inclined to avert the use of FTs should they themselves suffer from advanced dementia, compared to only 8.5% who would be prepared to have an FT themselves in these circumstances. Do doctors have a different approach to treating themselves compared to their patients? Or are they incapable of resisting environmental pressure (i.e., work procedures, the health system, or the patient's family) and "reserve the right" to reach the "correct" decision only for themselves? This issue is worthy of further study.

Another interesting finding that has not been reported previously is that only a minority of doctors would agree that the medical team (15.4%) or their family members (7.0%) decide for them on the use of an FT, should they suffer from advanced dementia. This finding highlights the need to establish realistic expectations about the use of FTs in advance, on the part of patients and their relatives on the one hand and the medical team on the other. It also emphasizes the importance of implementing advance medical directives when patients are still at the stage of relatively mild dementia [45].

Most of the doctors noted that the most important factor that affects their decision on the use of an FT, should they themselves suffer from advanced dementia, is the medical education that they received (50.7%). Previous studies have shown that intervention programs designed to improve the level of doctors' knowledge about the use of FTs in patients with advanced dementia succeeded in changing the attitudes of these doctors and reduced the use of FTs significantly [46, 47]. The finding that most of the doctors had only partial knowledge about the use of FTs strengthens the need to raise their level of knowledge on this subject during residency training and throughout the years of continuing medical education.

This study has several advantages. It included a relatively large sample of doctors with a response rate >80%, in contrast to previous studies in which the response rate ranged between 28 and 53% [37, 48, 49]. We also had a low number of incomplete responses and equal representation of hospital-based and community-based doctors, and of board-certified





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doctors and residents. To our knowledge, this is the first study in Israel that has evaluated the knowledge and attitudes of a large and varied group of doctors on the subject of FTs.

The study also has limitations. First, regarding the sample population, the investigators did not have access to the medical-team meetings in all of the small clinics and not all doctors attended the meetings at which the questionnaire was administered. This limits our ability to generalize the results from this population to all doctors. Another significant limitation stems from the nature of the study. We assessed the knowledge and attitudes of doctors, but not their actual practice in the clinical setting. Thus, we cannot determine if the results of the study reflect a lack of experience on the part of doctors in the treatment of patients with advanced dementia, or a lack of sufficient training in this area. Finally, the small number of doctors with "sufficient knowledge" did not enable us to conduct further analyses on the factors that influence the use of FTs.

Conclusions

The results of this study demonstrate large gaps in knowledge among doctors on enteral feeding for patients with advanced dementia. They highlight the need for the development of a training program for doctors on the treatment of patients with advanced dementia in general, and enteral feeding in particular. To improve the current situation, guidance should also be provided for patients, especially those in the early stages of cognitive decline. Efforts should also be invested to promote the awareness of advanced medical directives.

Disclosure Statement

The authors report no conflicts of interest.

Funding Sources

There was no funding.

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Dement Geriatr Cogn Disord Extra 2018;8:268–276				
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