

Decision-making for long-term tube-feeding in cognitively impaired elderly people

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Abstract

Background: The decision to start long-term tube-feeding in elderly people is complex. The process by which such decisions are made is not well understood. The authors examined the factors involved in the decision to start long-term tube-feeding in cognitively impaired older people from the perspective of the substitute decision-maker.

Methods: A telephone survey was administered to the substitute decision-makers of tube-fed patients over 65 years old in chronic care facilities in Ottawa. Subjects were recruited from September 1997 to March 1998. Patients were incapable of making their own decisions about tube-feeding. Data were collected on sociodemographic factors, patients' health status, advance directives, communication between the substitute decision-maker and the health care team, and the decision-maker's perceived goals of tube-feeding and satisfaction with the decision regarding tube-feeding.

Results: Among the 57 cases in which the patient was eligible for inclusion in the study, 46 substitute decision-makers agreed to participate. Most of the patients had not given advance directives, and only 26 substitute decision-makers (56.5%) were confident that the patient would want to be tube-fed. A physician spoke with the substitute decision-maker about tube-feeding for 15 minutes or less in 17 cases (37.0%) and not at all in 13 cases (28.3%). Most of the substitute decision-makers (39 [84.8%]) felt that they understood the benefits of tube-feeding, but less than half (21 [45.7%]) felt that they understood the risks. The prevention of aspiration and the prolongation of life were the medical benefits most often cited as reasons for tube-feeding. Just over half (24 [52.2%]) of the substitute decision-makers felt that they had received adequate support from the health care team in making the decision. Substitute decision-makers of patients less than 75 years old were more likely than those of older patients to feel supported (odds ratio [OR] 4.2, 95% confidence interval [CI] 1.0–17.9). Compared with the physician's making the decision independently, substitute decision-makers felt more supported if they primarily made the decision (OR 16.5, 95% CI 2.7–101.4) or if they made the decision together with the physician (OR 5.3, 95% CI 1.0–27.9). Most (20 [43.5%]) of the substitute decision-makers did not feel that tube-feeding improved the patient's quality of life, and less than half (21 [45.7%]) indicated that they would choose the intervention for themselves.

Interpretation: The substitute decision-making process for tube-feeding in cognitively impaired elderly people is limited by a need for advance directives, lack of confidence in substituted judgement and poor communication of information to the substitute decision-maker by the health care team.

The decision of whether to start long-term tube-feeding in a cognitively impaired older person who is unable to eat independently is complex. About 10% of elderly people living in chronic care facilities in Ontario are tube-fed. However, there is little evidence to support the putative benefits of long-term tube-feeding, such as the prevention of aspiration¹⁻¹⁰ and the prolongation of life.^{11,12} Long-term tube-feeding represents a considerable expense to the health care system and may be burdensome to the patient. At the time of the decision, the patient's wishes about tube-feeding are often not known. Given these uncertainties, it is unclear how decisions to start long-term tube-feeding are being made.

Earlier investigations examining the decision-making process regarding tube-feeding were based primarily on the attitudes of substitute decision-makers,^{13,14} health care



Evidence

Études

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professionals¹⁴⁻¹⁷ or cognitively intact older people^{14,18,19} toward hypothetical scenarios. However, responses to theoretical vignettes do not necessarily reflect choices made in real situations. To our knowledge, no published study has examined the decision-making process based on the actual experiences of substitute decision-makers.

To address this issue, we surveyed the substitute decision-makers of cognitively impaired tube-fed elderly people living in chronic care facilities in Ottawa. We examined the factors that influenced the decision to start tube-feeding, the extent to which the substitute decision-maker felt supported by the health care team and the level of satisfaction with the decision. This type of information is necessary to improve this complex decision-making process²⁰ and should lead to better outcomes for tube-fed older people.

Methods

All tube-fed patients in Ontario institutions are designated as requiring "chronic care." Therefore, we surveyed the substitute decision-makers of tube-fed elderly patients living in chronic care facilities in Ottawa from September 1997 to March 1998. Tube-fed patients who had died during the year before September 1997 were also included. Most of the chronic care beds (577) are located at a single institution. A smaller facility has 183 chronic care beds, and 3 of the acute care hospitals have a combined total of about 60 beds for patients awaiting long-term placement. Study approval was obtained from the institutional review board of each facility.

In the chronic care hospitals we identified the tube-fed patients from computerized lists generated by the departments of nutrition. In the acute care facilities the medical directors of the individual long-term-care units provided a list of tube-fed patients. Tube-fed patients who had died in the last year were recruited only from the chronic care hospitals. They were identified by matching the medical record numbers of all tube-fed patients in the facility over the past year with those of the patients who had died.

We conducted a chart review to determine the patients' eligibility for the study. Eligibility criteria included age over 65 years when the tube was placed, tube-feeding for at least 2 months, inability to make medical decisions at the time the tube was placed, and availability of the name and location of the substitute decision-maker. We determined decision-making capability by reviewing the medical record and, if necessary, by directly discussing the case with the nurse or physician involved in the care of the patient. Cases in which decision-making capability was ambiguous were excluded.

The charts of eligible patients were also abstracted for age and sex, the primary diagnosis that resulted in the need for tube-feeding, the type of feeding tube, the duration of tube-feeding and the facility where the tube was inserted. Diagnoses were categorized as acute neurologic or psychiatric events (stroke, head injury and acute depression), chronic dementing processes (Alzheimer's disease and other forms of dementia) and mechanical problems (obstruction, Parkinson's disease and neuromuscular disorders).

The substitute decision-maker was considered the person designated by the patient to make the patient's health care decisions. If there was no such person, the substitute decision-maker was considered to be the person who signed the consent form for feeding-tube placement. A letter was sent to the substitute decision-makers of eligible patients explaining the purpose of the survey, and they were contacted by telephone 1 week later. Substitute decision-makers were considered eligible if they could

communicate in English and if they were capable of giving consent.

Interviews were conducted over the telephone by one of 2 geriatricians (S.L.M. or F.M.E.L.), who were not previously familiar with the patient's case. The survey was divided into 6 sections: health status of the patient, advance directives, communication with the health care team, perceived goals of tube-feeding, satisfaction with the decision to start tube-feeding and sociodemographic data. Most of the questions were closed, although some were open-ended (described in the following paragraphs).

In the section on health status, the substitute decision-maker was asked the proportion of the day the patient was in bed and the extent to which the patient was aware of his or her surroundings. The section on advance directives sought information on whether the patient had chosen a substitute decision-maker, whether the patient had a living will and whether the patient had previously communicated his or her wishes concerning long-term tube-feeding. The substitute decision-makers were also asked how confident they were that the patient would have wanted a feeding tube if he or she had been able to make medical decisions.

In the section on communication, the substitute decision-makers were asked which physician spoke with them about the decision to start tube-feeding and for how long, and whether they felt they had understood the risks and benefits of tube-feeding. The involvement of other team members, including nurses, social workers, clergy, dietitians and speech pathologists, was also determined.

The substitute decision-makers were asked who they perceived made the decision to start tube-feeding, whether they felt that they had received the right amount of support from the health care team and whether they felt pressured into the decision. They were also asked what they found particularly useful or unhelpful about the support they received, and suggestions to improve the process were solicited in an open-ended fashion.

The level of satisfaction with the decision to start tube-feeding was determined by asking how strongly for or against the intervention the substitute decision-maker was at the time of the survey compared with when the decision was made. Finally, the substitute decision-makers were asked whether they would want to be tube-fed if they were in the same condition as the patient and whether they felt that tube-feeding had improved the patient's quality of life.

Descriptive statistics were obtained for all variables. We used unadjusted logistic regression to measure the association between individual variables and the substitute decision-makers' perception that they had adequate support. Factors that were significantly associated ($p < 0.05$) with adequate support were entered into a forward stepwise logistic regression to determine the best set of independent factors associated with this outcome. Continuous variables (age of patients and of substitute decision-makers, and duration of tube-feeding) were dichotomized based on their median values.

Results

We identified 120 tube-fed patients who were living (97 patients) or who had died (23 patients) in the year before the survey at chronic care facilities in Ottawa. Of these, 63 were ineligible for the survey, for the following reasons: age less than 65 years when the tube was inserted (31 cases), patient capable of making medical decisions (23 cases), inadequate information to contact substitute decision-maker (4 cases), duration of tube-feeding less than 2 months (3 cases), and substitute decision-maker could not communicate in English (1 case) or give consent (1 case).



Among the 57 eligible cases 11 substitute decision-makers refused to participate. This left 46 to complete the survey.

The characteristics of the patients and their substitute decision-makers are given in Table 1. The mean age of the patients when the tube was placed was 76.0 (standard deviation [SD] 7.1) years (range 65–92 years), and the mean duration of tube-feeding was 28.6 (SD 34.6) months (range 2–151 months). In most cases the tube was placed while the patient was in an acute care setting. An acute neurologic or psychiatric event was the most common diagnosis (stroke in 32 cases, head injury in 1 and depression in 1).

Although 27 patients (58.7%) had previously chosen a substitute decision-maker, only 11 (23.9%) had a living will (Table 2). Only 1 patient had specifically mentioned wishes about long-term tube-feeding (did not want to be tube-fed). Twenty-six substitute decision-makers (56.5%) felt

confident that the patient would have opted for tube-feeding had he or she been capable of making the decision.

The patient's primary care physician was the doctor who most often discussed the tube-feeding decision with the substitute decision-maker (21 cases [45.6%]) (Table 2). A substantial proportion of the substitute decision-makers (13 [28.3%]) did not speak or did not remember whether they spoke to a physician about the decision.

Although most of the substitute decision-makers felt

Table 1: Characteristics of 46 tube-fed cognitively impaired elderly people in chronic care facilities in Ottawa and their substitute decision-makers

Characteristic	No. (and %) of subjects
Patients	
Age \geq 75 yr when tube placed	24 (52.2)
Female sex	30 (65.2)
Alive when survey conducted	35 (76.1)
Tube inserted in acute care setting	43 (93.5)
Tube in place for \geq 12 mo	24 (52.2)
Type of tube	
Percutaneous gastrostomy	35 (76.1)
Jejunostomy	11 (23.9)
Primary diagnosis	
Acute neurologic or psychiatric event*	34 (73.9)
Progressive dementia†	5 (10.9)
Mechanical swallowing problem‡	7 (15.2)
Over half the day spent in bed	39 (84.8)
Aware of surroundings	
Not at all	19 (41.3)
Somewhat	21 (45.6)
Very	6 (13.0)
Substitute decision-makers (SDMs)	
Age \geq 50 yr	22 (47.8)
Female sex	34 (73.9)
Relationship to patient	
Child	32 (69.6)
Spouse	8 (17.4)
Other	6 (13.0)
Education	
Did not complete high school	6 (13.0)
High school graduate	13 (28.3)
Postsecondary	27 (58.7)
Religion	
Catholic	21 (45.7)
Protestant	20 (43.5)
Other	5 (10.9)

*Stroke, head injury or depression.

†Alzheimer's disease or other dementia.

‡Obstruction, Parkinson's disease, amyotrophic lateral sclerosis or other neuromuscular problem.

Table 2: Factors involved in decision-making process for long-term tube-feeding

Factor*	No. (and %) of SDMs
Advance directives	
Patient had formally chosen SDM	27 (58.7)
Patient had a living will	11 (23.9)
SDM confident that patient would want tube-feeding	26 (56.5)
Communication with health care team	
Physician who discussed decision with SDM	
Primary care physician	21 (45.7)
Consultant who inserted tube	13 (28.3)
Resident or intern	2 (4.3)
None	10 (21.7)
Amount of time spent discussing decision with physician	
None or did not remember	13 (28.3)
\leq 15 min	17 (37.0)
$>$ 15 min	16 (34.8)
Decision discussed with any other team member†	31 (67.4)
Risks and benefits	
SDM understood risks	21 (45.7)
SDM understood benefits	39 (84.8)
Main reason for tube-feeding	
Prolong life	37 (80.4)
Fulfil moral obligation	36 (78.3)
Prevent aspiration	33 (71.7)
Provide nourishment	22 (47.8)
Make it easier for staff to feed patient	21 (45.7)
Decision support	
SDM felt supported	24 (52.2)
SDM felt pressured	12 (26.1)
Person who made decision	
Primarily SDM	15 (32.6)
SDM and physician together	13 (28.3)
Primarily physician	18 (39.1)
Satisfaction with decision	
SDM would want tube-feeding for her- or himself	21 (45.7)
SDM felt she or he made the best decision	36 (78.3)
SDM against tube-feeding at time of decision	4 (8.7)
SDM against tube-feeding in retrospect	10 (21.7)
Tube-feeding improved patient's quality of life	
Yes	17 (37.0)
No	20 (43.5)
Unsure	9 (19.6)

*Factors reflect SDMs' perceptions of these issues with respect to the decision to start tube-feeding.

†Nurse, social worker, clergy, dietitian or speech pathologist.



that they understood the benefits of tube-feeding, less than half (21 [45.7%]) felt that they understood the risks. The only risks the substitute decision-makers remembered being explained to them were local complications of the tube (e.g., the tube falling out or local infections). The medical benefits that were most often cited were prolongation of life and prevention of aspiration (Table 2). In addition, 36 substitute decision-makers (78.3%) felt that there was a moral obligation to tube-feed.

About half of the substitute decision-makers felt that they had the right amount of support from the health care team to make the decision regarding tube-feeding (Table 2). The suggestions most often given to improve the decision-making process were more complete explanation of the risks and benefits (23 cases [50.0%]), more information on alternatives to the procedure (21 [45.7%]), further discussion of the long-term implications of tube-feeding (13 [28.3%]), longer time to make the decision (9 [19.6%]) and greater input from other health care professionals (8 [17.4%]).

Roughly equal numbers of substitute decision-makers felt that they had primarily made the decision to tube-feed, that they had made the decision on an equal basis with the doctor and that the physician had primarily made the decision (Table 2). Only 21 substitute decision-makers (45.7%) stated that they would want to be tube-fed if they were in the same condition as the patient, and 17 (37.0%)

felt that tube-feeding improved the patient's quality of life.

Communication factors that were significantly associated with a sense of adequate support for decision-making on the part of the substitute decision-maker in the unadjusted analyses included an understanding of the risks of tube-feeding, a feeling that one was not pressured into the decision, greater time talking to a physician, and a sense that one participated in the decision (Table 3). The only characteristic of patients or substitute decision-makers significantly associated with adequate support was patient's age less than 75 years (odds ratio [OR] 3.5, 95% confidence interval [CI] 1.0–11.8).

In the multivariate analysis, only patient's age less than 75 years (OR 4.2, 95% CI 1.0–17.9) and person who made the decision remained independently associated with a feeling of receiving adequate support. Compared with the physician's making the decision independently, substitute decision-makers felt more supported if they primarily made the decision (OR 16.5, 95% CI 2.7–101.4) or if they made the decision together with the physician (OR 5.3, 95% CI 1.0–27.9).

Interpretation

It is critical that decisions about tube-feeding in elderly people be made appropriately. Despite ethical and legislated guidelines for surrogate decision-making,^{21,22} we found that the process was poorly implemented owing to inadequate advance directives, lack of confidence in substituted judgement and insufficient information provided to the substitute decision-makers about tube-feeding. It is not surprising that only half of the substitute decision-makers felt that they had adequate support to make the decision.

Principles for substitute decision-making for cognitively impaired elderly people give priority to the previously expressed wishes of the patient.^{21,22} Adherence to this principle was seriously limited in our study because most patients had not prepared an advance directive. Furthermore, only 1 patient had specifically expressed wishes regarding long-term tube-feeding to the substitute decision-maker before becoming ill. Of concern was our finding, similar to that of others,²³ that only half of the substitute decision-makers were confident that the patient would want to be tube-fed. In the absence of advance directives, the principle of "substituted judgement" dictates that decisions should be based on what the substitute decision-maker feels the patient would choose if she or he were competent. However, it is impossible for substitute decision-makers to adhere to this principle without adequate preparatory discussions with their dependents. Interestingly, some studies have shown that substitute decision-makers do not necessarily consider the patient's advance directives even when available.^{18,23,24} In addition, it has been reported that the substitute decision-maker's perception of what the patient would want is not always concordant with the patient's wishes.²⁵

When there is insufficient information to employ advance directives or substituted judgement, substitute decision-makers should base their decisions on what they understand to be in the patient's best interest.^{21,22} In our study

Table 3: Association between factors involved in communication with the health care team and the SDM's perception of adequate support for the tube-feeding decision

Factor	No. (and %) of SDMs who received adequate support	Crude odds ratio (and 95% CI)
SDM understood benefits		
Yes	23/39 (59.0)	8.6 (0.9–78.7)
No	1/7 (14.3)	1.0
SDM understood risks		
Yes	15/21 (71.4)	4.4 (1.3–15.5)
No	9/25 (36.0)	1.0
SDM felt pressured		
No	22/34 (64.7)	9.2 (1.7–48.8)
Yes	2/12 (16.7)	1.0
Amount of time spent discussing decision with physician		
None or did not remember	3/13 (23.1)	1.0
≤ 15 min	8/17 (47.1)	3.0 (0.6–14.7)
> 15 min	13/16 (81.2)	14.4 (2.4–87.4)
Person who made decision		
Primarily physician	4/18 (22.2)	1.0
SDM and physician together	8/13 (61.4)	5.6 (1.2–27.1)
Primarily SDM	12/15 (80.0)	14.0 (2.6–75.4)
Decision discussed with any other team member		
Yes	19/31 (61.3)	3.2 (0.9–11.5)
No	5/15 (33.3)	1.0

Note: CI = confidence interval.



the principle of best interest was seriously hindered by potentially inadequate and inaccurate information communicated by the health care team. Like Schonwetter and colleagues,²³ we found that most of the substitute decision-makers felt that they understood the benefits but not the risks of the procedure. However, the medical benefits most often cited by physicians — the prevention of aspiration¹⁻¹⁰ and the prolongation of life^{12,13} — are not clearly supported in the literature. In our study the only risks the substitute decision-makers remembered being explained to them were local complications of the tube. Diarrhea, aspiration and agitation necessitating physical or chemical restraints are also important potential complications in older people.^{26,27}

Once informed, the substitute decision-maker must weigh the possible medical outcomes against the perceived values and preferences of the patient. In this respect, the effect of tube-feeding on the patient's quality of life and functional status may be the most relevant outcomes to consider. Most of the respondents in our study did not feel or were unsure whether tube-feeding improved the patient's quality of life. Weaver and associates²⁸ found that tube-feeding subjectively improved quality of life in only 28% of tube-fed patients over 75 years. A lack of "meaningful" recovery may be reflected in the fact that, in our study, only half of the substitute decision-makers felt that they would want to be tube-fed if they were in the patient's condition.

Potential limitations of our study warrant comment. First, the data are based only on the perceptions and recollections of the substitute decision-makers. Therefore, there is the potential for recall bias. Second, the decision-making process may differ in other populations or settings. In most cases the decision regarding tube-feeding took place in the acute care setting, usually owing to complications of a stroke. This is in contrast to reports from the United States, where progressive dementia is frequently an indication for long-term tube-feeding.^{4,5} Under these circumstances the decision is often made in a nursing home and therefore may be less rushed than in an acute care hospital. Finally, it would be interesting to examine the tube-feeding decision-making process among substitute decision-makers who were offered the intervention but decided to decline.

Regardless of setting or indication, the use of long-term tube-feeding in elderly people has important implications from a variety of perspectives, including health care costs to society and the quality of life of patients. Thus, decisions about tube-feeding must be made with care. It is critical that the principles of substitute decision-making be respected. Our findings highlight the need for comprehensive advance directives, improved education regarding surrogate decision-making, and more complete and accurate communication of information to the substitute decision-maker by the health care team. Future work should focus on the development of innovative methods of support aimed at guiding this decision-making process.

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