Tube feeding controversial patients: what do dietitians think?

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Abstract

The use of tube feeding in some patients can be controversial, however, few studies have investigated dietitians' opinions on this subject. A cross-sectional survey of 345 members the Irish Nutrition and Dietetic Institute was conducted using a self-administered, anonymous, postal questionnaire. A 44% response rate was achieved. Mean number of years qualified was 9.3 (8.4). Eighty-one per cent of responders were involved in initiating tube feeding in stroke patients, and 8.5% in discontinuing tube feeding in a patient in a persistent vegetative state (PVS). Nine per cent felt that their input had no influence on the care plan of the patient with dementia and 67% felt that the information given to families (or other decision makers) concerning tube feeding was inadequate. The majority of respondents favoured tube feeding fictitious stroke and cancer patients, but less than half favoured tube feeding a fictitious patient in a PVS or a patient with dementia. When given similar scenarios involving themselves, fewer dietitians wanted to be tube fed.

Background

Long-term tube feeding is an integral part of the management of many patients with chronic illness. In the majority of cases the decision to tube feed is made with relative ease, however, in a growing number of cases the decision is becoming an ethical, legal, professional and personal dilemma for all involved (Ravenscroft & Bell, 2000).

For patients with certain chronic and acute illnesses, i.e. with terminal cancer, following stroke, with dementia and in persistent vegetative state (PVS) feeding may constitute an ethical dilemma for carers if the management of the patient (including tube feeding) is not put into the context of the overall medical plan (Brody & Noel, 1991).

Health professionals have been found to be more likely to choose tube feeding for their patients that for themselves (Asai *et al.*, 1999; Mitchell *et al.*, 2000). Studies have also found a major difference in the choices made by decision makers for the patient and what the patient would choose for themselves. In addition, elderly patients have been found to be less concerned with the symbolic meaning of tube feeding than physicians think they are (Carmel, 1999).

It is assumed that at least 25 000 people are suffering from dementia in Ireland (Wrigley, 1995). An unpublished audit of patients leaving a large Dublin teaching hospital on tube feeding found that 10% of patients have tubes inserted as a result of dementia (McNamara & Kennedy, 2001). In Britain about two-thirds of those with Alzheimer's disease will spend the last 1–3 years of their lives or longer in hospitals, nursing homes or residential homes possibly with some aspect of

impaired ability to eat (Lennard-Jones, 1998). Research conducted in Germany has shown that 40–50 per 100 000 nursing home beds are taken up by dementia patients who have had percutaneous endoscopic gastrostomies (PEG) inserted (Lindemann & Nikolaus, 2001). Patients with dementia are most frequently commenced on tube feeding with the objective of preventing aspiration pneumonia, malnutrition, skin breakdown and pressure sores and ultimately improving survival (Mitchell *et al*., 1997; Finucane *et al*., 1999). However, the evidence highlights its lack of success in these areas (Mitchell *et al*., 2000).

The aim of this study was to look at this emerging area of nutritional support in Ireland and how it is dealt with by dietitians. While dietitians are responsible for the nutritional requirements of patients, little is known of their input into the decision-making process regarding the overall management of their patients. Considering the fact that so little is known about the opinions and practices of Irish dietitians regarding the use of tube feeding these patients, this study had three objectives. First, we wished to establish the experience of dietitians in caring for these potentially difficult patients. Secondly, we wished to ascertain if dietitians followed any policy in the care of these patients. Lastly, we wanted to examine dietitians personal attitudes towards tube feeding patients and themselves under certain conditions.

Methods

Subject selection

The Irish Nutrition and Dietetic Institute (INDI) is the professional body for dietitians in Ireland. There are approximately 345 members of the INDI at present. The vast majority of working dietitians in Ireland are members of the INDI.

Questionnaire design

In designing the questionnaire a number of factors had to be considered in order to ensure as high as possible response rate and to ensure that the aims and objectives of the survey were met. Questionnaires should be appropriate, intelligible, unambiguous, unbiased, omnicompetent, piloted before use and finally questions should be ethical (Stone, 1993). The layout of the questionnaire was carefully designed as the visual impact can either arouse interest or alternatively discourage participation (Fitzpatrick, 1991). Although the questionnaire did refer to four main situations of ill health; stroke, end-stage dementia, terminal cancer and PVS, the main body referred only to end stage dementia, as the use of tube feeding in the patient with dementia has been challenged in recent years (Finucane *et al*., 1999). It was decided that similar sections on the other conditions should not also be included as cooperation in self-administered questionnaires may decline if there are too many items or questions included (Fallowfield, 1995).

Because responses to open questions can be long, varied, difficult to compare with others and difficult to handle statistically (Bennet & Ritchie, 1975) the majority of questions asked were closed ended making them to clear and unambiguous and allowing simple dichotomous answers. Also in several different questions the Likert scale was used in 1–10 and 1–5 format where the respondents ticked the most appropriate of the scale, i.e. 1–5 scale corresponds with 'definitely no, probably no, unsure, probably yes and definitely yes'. In one section of the questionnaire, respondents were given the opportunity to expand on the Likert scale by introducing a comment option, which added more variety in question design.

Questionnaire content

The questionnaire, which was seven pages long, consisted of a number of sections which examined background information on each professional, experience to date in decisions to initiate and discontinue tube feeding, hospital policies in relation to the dietetic treatment of patients with end-stage dementia, case studies and personal wishes for tube feeding. Respondents were invited to make further comments if they wished.

Questionnaire pilot and delivery

The self-administered, anonymous questionnaire was first piloted on a small sample of dietitians

practising in community and clinical settings and then revised where appropriate. A questionnaire and a cover letter outlining the background to and aims of the project was posted to each subject. A return envelope was included to improve the response rate.

Statistical analysis

Returned questionnaires were coded, and data were entered and analysed using SPSS version 10.0 for Windows. Statistical tests used included general descriptive statistics, chi-squared and Student's *t*-tests (parametric data) and the Kruskal–Wallis and Mann–Whitney *U*-tests (nonparametric tests). A *P*-value of < 0.05 was deemed to be significant. All additional comments made by dietitians on the questionnaire were transcribed and analysed by hand.

Results

Response rate

Of the 345 questionnaires posted, 155 were returned, giving an initial response rate of 45%. Two questionnaires were excluded from the analysis, as one was returned unfilled without explanation and the second stated that their experience in the area was limited. This left an analysable response rate of 44%. A profile of respondents is presented in Table 1.

Table 1 Profile of the respondents

	n (%)
Area of work	
Community dietetics	20 (13)
Clinical dietetics	107 (70)
Other areas	26 (17)
Years qualified	
< 6 years	63 (41)
6 and 10 years	47 (31)
Over 10 years	43 (28)
Specialization	
Paediatrics	23 (15)
Elderly	15 (10)
Cardiology	15 (10)
Other	100 (65)

Experience to date

Dietitians were asked about their experience initiating and discontinuing tube feeding in-patients with stroke, end-stage dementia and terminal cancer and PVS (Table 2). Only 23 (15%) had ever been involved in discontinuing tube feeding in patients with end-stage dementia with more dietitians involved in discontinuing tube feeding in patients following stroke than any other condition ($n = 58$, 38%). The largest number of dietitians involved in initiating tube feeding were also those involved with stroke patients ($n = 124$, 81%). A surprisingly high number ($n = 38$, 24%) were involved in initiating tube feeding in PVS patients, while 8.5% ($n = 13$) were involved in discontinuing tube feeding in this group.

Hospital policies

Respondents were asked if they used an artificial nutrition and hydration policy regarding the nutritional management of patients with dementia in their workplace. Seventy-eight per cent of the respondents reported ($n = 119$) that there was no policy in their workplace, whereas 21% ($n = 32$) stated that they did not know if such a policy existed. Only one respondent reported that there was a policy in their place of work.

Decision making – dietetic involvement

Forty-one per cent ($n = 63$) of the sample were involved in the initiation or discontinuation (or

Table 2 Respondent exposure to patient types

	Stroke (%)	End-stage dementia (%)	Terminal cancer (%)	PVS (%)
Involved in initiating tube feeding?				
Yes	81	40	53	24
No	14	56	43	71
Unsure	5	4	4	5
Total	100	100	100	100
Involved in discontinuing tube feeding?				
Yes	38	15	29	9
No	58	80	67	87
Unsure	4	5	4	4
Total	100	100	100	100

both) of tube feeding of patients with advanced dementia. Thirty per cent of this group ($n = 19$) felt that they were not adequately involved in the decision-making process, while 24% ($n = 15$) were unsure of their influence. A further 9% ($n = 6$) felt that their input had no influence on the care plan of the patient with dementia. The majority of respondents ($n = 103$, 67%) felt that the information given to families (or other decision makers) concerning tube feeding was inadequate. The majority of dietitians reported that the discussion and communication amongst the medical team regarding tube feeding dementia patients was insufficient ($n = 89$, 58%). However, some respondents did state that this was dependant on the hospital and the medical team concerned.

Decision making – dietitians' opinions

Dietitians were given four different patient scenarios (Appendix 1), and asked to state how they would treat the patient each time, based on a scale of 1–10, where 1 was 'strongly in favour' and 10 was 'strongly opposed'. Figure 1 graphically displays the opinions of the dietitians regarding the use of tube feeding in the scenarios.

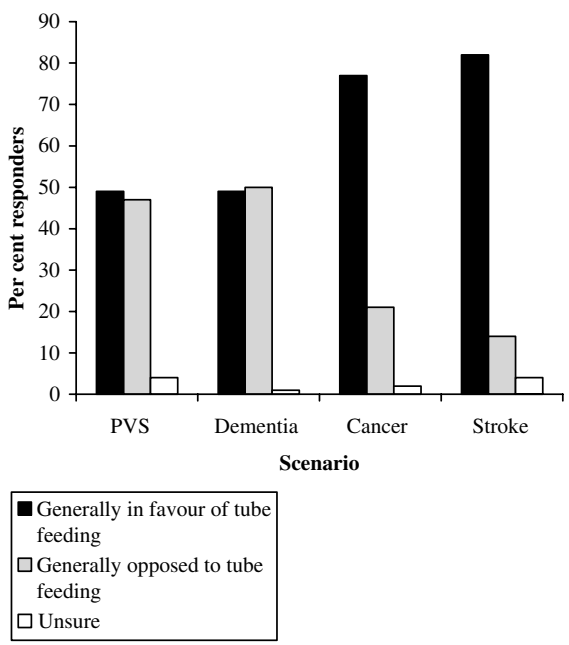

Figure 1 Dietitians opinions on tube feeding patients in certain scenarios (Appendix 1).

As a group, dietitians were generally neither in favour nor opposed to continuing PEG feeding in the PVS patient (Appendix 1). Forty-eight per cent ($n = 74$) were in favour and 47% ($n = 72$) were opposed. Of the 141 respondents who commented on why they chose to feed or not, the major reason cited by dietitians opposing discontinuation was the belief that it would be unethical to allow the patient to starve to death ($n = 16$, 11%). The patients' poor prognosis and remote possibility of improvement were the most common reasons to favour discontinuing the feed. Thirty-five per cent of the dietitians ($n = 54$) said that the wishes of the patients' family members would be the most influential factor on their decision. Neither numbers of years qualified nor previous involvement in the initiation or discontinuation of tube feeding a PVS patient were found to influence decisions to continue tube feeding.

A similar result was found in relation to the patient in end-stage dementia as 49% ($n = 75$) were in favour and 50% ($n = 77$) were opposed to initiating tube feeding. The two main reasons cited by those opposed to initiating tube feeding were that the patient's quality of life is unlikely to improve ($n = 19$, 25%) and the assumption that the patient does not want to live because of her refusal to eat ($n = 8$, 11%). The most common reason to favour initiating tube feeding was the belief that withholding the feed would cause starvation, which is unethical, inhumane and a form of neglect ($n = 9$, 12%).

The majority of dietitians were in favour of tube feeding the patient with cancer ($n = 118$, 77%). Respondents who were never involved in the care of cancer patient on tube feeds ($n = 48$) were more likely to be opposed to tube feeding this patient however ($P < 0.05$). The main reason for opposing tube feeding was the belief that it would not improve the patients comfort and would exacerbate her gastrointestinal symptoms, with 10% ($n = 4$) of those opposing tube feeding citing this as the reason. The belief that tube feeding may reduce pressure on the patient to eat large amounts of food and therefore reduce her fatigue ($n = 13$, 11%) and that it may improve her quality

of life, comfort and increase her longevity ($n = 38$, 32%) were the two most common reasons cited by those who supported tube feeding this patient. Dietitians generally favoured tube feeding the patient suffering from dysphagia following stroke [82% ($n = 125$) were in favour, 14% ($n = 22$) opposed, and 4% ($n = 6$) unable to decide].

Personal wishes to be tube fed

Sixty-seven per cent of respondents ($n = 118$) said that they had never expressed wishes to a family member or friend regarding their wishes for tube feeding. Respondents were asked to consider themselves in four states of ill-health: PVS, end-stage dementia, terminal cancer and stroke. Each scenario was very short, but similar to the versions in Appendix 1. Subjects were asked to score their preference for tube feeding on a 5-point scale from 'definitely no' to 'definitely yes'.

The majority of respondents ($n = 112$, 73%) did not want to be tube fed if they were in a PVS. It was clear that dietitians were more likely to want tube feeding for the PVS patient ($n = 73$, 48%) than for themselves ($n = 25$, 16%) ($P < 0.001$). In relation to end-stage dementia, the majority of dietitians said that they would not want to be tube fed ($n = 106$, 69%). Dietitians were more likely to want to feed the patient in the scenario ($n = 75$, 49%), than themselves ($n = 28$, 18%) ($P < 0.001$). The majority of dietitians would want to be tube fed themselves in the stroke scenario ($n = 121$, 79%). In the final case, dietitians were again more likely to want to feed the patient with cancer ($n = 118$, 77%), than themselves ($n = 55$, 36%) ($P < 0.001$). Previous experience with cancer patients significantly affected respondents choices for tube feeding themselves – those dietitians who had dealt with cancer patients were more likely to want to be tube fed themselves. Figure 2 compares dietitians' wishes for themselves and for their patients.

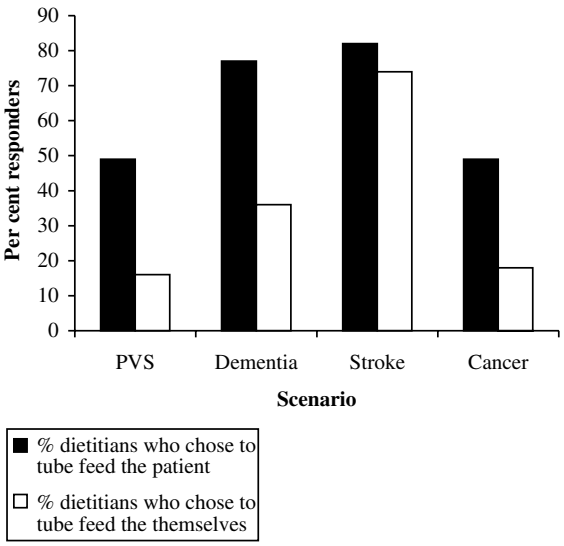

Figure 2 Dietitians opinions about tube feeding patients compared with opinions on tube feeding themselves.

Discussion

Considering the significant role of the dietitian in the care of any patient on tube feeding, their opinions on the use of tube feeding in potentially controversial patients is important. Surprisingly few studies have looked at the involvement of dietitians in the decision to tube feed patients of any type. It was hoped that this study might uncover some detail about the dietitian's role in the decision process to tube feed dementia patients, in addition to finding out how dietitians feel about tube feeding certain patients and themselves.

The response rate to the survey (45%) compares well with a similar survey of members of the American Dietetic Association Nutrition Support Practice Group (Wall *et al.*, 1991) and to comparable studies of other health professionals (Von Preyss-Friedman *et al.*, 1992; Grubb *et al.*, 1996). It was surprising that 24% of respondents had experience in initiating tube feeding in a PVS patient, and that 8.5% were involved in discontinuing tube feeding in these patients, considering the relatively small number of such patients. The small number of dietitians who reported being involved in discontinuing tube feeding in a dementia patient (15%) despite the fact that so many more were involved in initiating tube feeding in this group (40%) perhaps reflects how infrequently these patients discontinue tube feeding once it has commenced.

Ravenscroft & Bell (2000) have stated that there is a clear lack of formal guidelines for withdrawing life-sustaining treatments, especially artificial

nutrition and hydration in Britain. The fact that 78% of our respondents reported to have no formal artificial nutrition and hydration policy for the management of dementia patients was not surprising therefore. The American Dietetic Association (1995) have stated that the dietitian must provide education regarding nutrition and hydration issues, serve as a patient advocate, and participate in the legal and ethical issues regarding feeding. However, the results of the present study reveal that many Irish dietitians find it difficult to fulfil this role, as almost one-third felt that they were not adequately involved in the decision-making process and were either unsure of their influence or felt they had no influence on the care plan for a patient with advancing dementia.

Many respondents felt that the information given to family members or other decision makers regarding tube feeding those with end-stage dementia was minimal (67%) and that discussion and communication with the medical team regarding this was inadequate (58%). Similar results have been found by other authors (Baker *et al*., 2000; Mitchell *et al*., 2000). Just under a quarter of our respondents stated that they did not discuss tube feeding with the family of the last patient with advanced dementia for whom tube feeding was part of their care plan. Delivering care that is consistent with patient preferences is an important component in the quality of end of life care, which requires effective communication (Covinsky *et al*., 2000). It is widely accepted that open communication and provision of information can promote understanding and deal with conflicting perceptions of treatments (Carmel, 1999). Although clear guidelines are not always possible, appropriate decisions regarding any form of life-sustaining treatment, including nutrition and hydration, require having productive moral conversations within the medical management team, of which dietitians are appropriate participants (Brody & Noel, 1991).

This group of Irish dietitians clearly displayed the two opposing sides of the argument in their feeding choices regarding patients in PVS. In a study of medical interns, the majority (80%) favoured withdrawing a tube feed in a PVS patient. Participants in the interns' study cited similar reasons for withdrawing the feed to the dietitians in this survey, i.e. the patient may have an irreversible disease and is unlikely to recover any significant function (Hodges *et al*., 1994). Just over a third of respondents in our study said that the most influential factor in decision making for the PVS patient would be the wishes of the family – a factor that others have noted (Grubb *et al*., 1996; Ryan & McNamara, 2001). In a study of Japanese physicians, only 3% favoured withdrawing a tube feed from a PVS patient (Asai *et al*., 1999), however, the numbers favouring withdrawal of the tube feed increased to 17% when both the family and the patient had expressed wishes on not wanting any form of sustaining treatment.

Irish dietitians were more inclined to want to tube feed a patient with end-stage dementia than a group of interns (Hodges *et al*., 1994) or a group of Irish nurses (Ryan & McNamara, 2001). Eleven per cent of respondents chose not to feed the patient because they assumed she did not want to live because of her refusal to eat. However, some authors believe that the refusal to eat may be caused by an accompanying depression, which may respond to drug treatment, and one cannot assume that the refusal of food necessarily reflects the wishes to die (Rosin & Sonnenblick, 1998). Other studies have also noted that family members repeatedly state that they cannot let a relative 'starve to death' and they often feel that they have no choice but to authorize tube feeding (Gillick, 2000), a fact also noted by 12% of dietitians in this study in relation to the dementia patient.

The number of dietitians who favoured tube feeding for the patients with cancer was high (77%) when compared with studies of Japanese American Physicians (11%) and Israeli Physicians (57%) (Asai *et al*., 1995; Carmel, 1999). In patients with advanced cancer, nutrition support may not only be ineffective in reducing morbidity and mortality, and reversing metabolic abnormalities but may even be associated with increased medical complications and reduction in quality of life (McCann *et al*., 1994). The majority of dietitians favoured tube feeding the stroke patient. This patient was aged 79 and the description of her condition was favourable, allowing for substantial improvement in her clinical condition. Therefore,

the fact that 14% were opposed to tube feeding this patient was quite high. Although only two responders cited the patients age to be the determining factor, this may have had an underlying effect on the decision not to initiate tube feeding. A similar patient condition (although not exactly the same) was described in another study, when 98% of interns favoured tube feeding (Hodges *et al*., 1994).

As seen in studies of physicians from different cultural backgrounds (Asai *et al*., 1995; Carmel, 1999) dietitians were more likely to want to tube feed their patients than themselves in all scenarios. One respondent noted 'I am amazed at how much I would not want tube feeding for myself, but so often am in a position where I feel I have to promote tube feeding for a patient in these situations'.

Dietitians qualified for 4 years or less were more likely to want to tube feed the cancer patient in the scenario given. A similar finding was found in a study of US dietitians (Wall *et al*., 1991). Those authors believed this to be because of the fact that older dietitians agreed that life itself may no longer benefit some patients, whereas younger dietitians may be more idealistic and aggressive in their views of nutrition therapy as seen in this study. Also, one could speculate that as one gains experience, one may also gain a greater appreciation of patient autonomy and one's ability to recognize deteriorating quality of life may increase.

It is hoped that this study will provide a starting point for discussion and education of dietitians regarding dilemmas in tube feeding. However, it is important to note the limitations of the study. First, the response rate, at 45%, while comparable with similar surveys in other countries was still quite low. Secondly, responder bias may have been a factor – those who chose to answer the questionnaire were probably more interested and/or involved in the area – thus the results may not reflect the views of all Irish dietitians. Lastly, we cannot equate hypothetical cases with real patients and dietitians may actually work differently in practice.

In conclusion, this study has uncovered some interesting findings about Irish dietitians' views about tube feeding. Most work without any guidelines or policies in terms of tube feeding patients with advanced dementia. More than half are either unsure of their involvement or do not feel involved in the decision-making process regarding tube feeding patients with advanced dementia. Most feel that families are not given enough information about the above issues. Compared with other studies, dietitians tend to be more in favour of tube feeding than other health professionals – although in every scenario given they were more likely to want to tube feed patients than themselves.

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References

American Dietetic Association (1995) Position of the American Dietetic Association: legal and ethical issues in feeding permanently unconscious patients. *J. Am. Diet. Assoc.* **95**, 231–234.

Asai, A., Fukuhara, S. & Lo, B. (1995) Attitudes of Japanese and Japanese-American physicians toward life-sustaining treatment. *Lancet* **346**, 356–359.

Asai, A., Maekawa, M., Akiguchi, I., Fukui, T., Miura, Y., Tanabe, N. & Fukuhara, S. (1999) Survey of Japanese physicians' attitudes towards the care of adult patients in persistent vegetative state. *J. Med. Ethic.* **25**, 302–308.

Baker, R., Wu, A.W., Teno, J.M., Kreling, B., Damiano, A.M., Rubin, H.R., Roach, M.J., Wenger, N.S., Phillips, R.S., Desbiens, N.A., Connors, A.F. Jr, Knaus, W. & Lynn, J. (2000) Family satisfaction with end-of-life care in seriously ill hospitalized adults. *J. Am. Geriatr. Soc.* **48**, S61–S69.

Bennet, A.E. & Ritchie (1975) Questionnaires in medicine. *A Guide to Their Design and Use*. Oxford: Oxford University Press.

Brody, H. & Noel, M.B. (1991) Dietitians' role in decisions to withhold nutrition and hydration. *J. Am. Diet. Assoc.* **91**, 580–585.

Carmel, S. (1999) Life-sustaining treatments: what doctors do, what they want for themselves and what elderly persons want. *Soc. Sci. Med.* **49**, 1401–1408.

Covinsky, K.E., Fuller, J.D., Yaffe, K., Johnston, C.B., Hamel, M.B., Lynn, J., Teno, J.M. & Phillips, R.S. (2000) Communication and decision-making in seriously ill patients: findings of the SUPPORT project. The study to understand prognoses and preferences for outcomes

and risks of treatments. *J. Am. Geriatr. Soc.* **48**, S187–S193.
Fallowfield, L. (1995) Questionnaire design. *Arch. Dis. Child.* **72**, 76–79.
Finucane, T.E., Christmas, C. & Travis, K. (1999) Tube feeding in patients with advanced dementia: a review of the evidence. *JAMA* **282**, 1365–1370.
Fitzpatrick, R. (1991) Surveys of patients satisfaction: II – designing a questionnaire and conducting a survey. *BMJ* **302**, 1129–1132.
Gillick, M.R. (2000) Rethinking the role of tube feeding in patients with advanced dementia. *NEJM* **342**, 206–210.
Grubb, A., Walsh, P., Lambe, N., Murrells, T. & Robinson, S. (1996) Survey of British clinicians' views on management of patients in persistent vegetative state. *Lancet* **348**, 35–40.
Hodges, M.O., Tolle, S.W., Stocking, C. & Cassel, C.K. (1994) Tube feeding. Internists' attitudes regarding ethical obligations. *Arch. Inter. Med.* **154**, 1013–1020.
Lennard-Jones, J.E. (1998) *Ethical and Legal Aspects of Clinical Hydration and Nutrition Support*. Maidenhead, UK: British Association of Parenteral and Enteral Nutrition.
Lindemann, B. & Nikolaus, T. (2001) Outcomes of percutaneous endoscopic gastrostomy in dementia patients. *J. Am. Geriatr. Soc.* **49**, 838–839.
McCann, R.M., Hall, W.J. & Groth-Juncker, A. (1994) Comfort care for terminally ill patients. The appropriate use of nutrition and hydration. *JAMA* **272**, 1263–1266.
McNamara, E. & Kennedy, N.P. (2001) Tube feeding patients with advanced dementia: an ethical dilemma. *Proc. Nutr. Soc.* **60**, 179–185.
Mitchell, S.L., Berkowitz, R.E., Lawson, F.M. & Lipsitz, L.A. (2000) A cross-national survey of tube-feeding decisions in cognitively impaired older persons. *JAGS* **48**, 391–397.
Mitchell, S.L., Kiely, D.K. & Lipsitz, L.A. (1997) The risk factors and impact on survival of feeding tube placement in nursing home residents with severe cognitive impairment. *Arch. Intern. Med.* **157**, 327–332.
Ravenscroft, A.J. & Bell, M.D. (2000) 'End-of-life' decision making within intensive care-objective, consistent, defensible? *J. Med. Ethics* **26**, 435–440.
Rosin, A.J. & Sonnenblick, M. (1998) Autonomy and paternalism in geriatric medicine. The Jewish ethical approach to issues of feeding terminally ill patients, and to cardiopulmonary resuscitation. *J. Med. Ethics* **24**, 44–48.
Ryan, A. & McNamara, E. (2001) Nurses opinions regarding the use of tube feeding in patients with advanced dementia. *Proc. Nutr. Soc.* **60**, 168A.
Stone, D.H. (1993) Designing a questionnaire. *BMJ* **307**, 1264–1266.
Von Preyss-Friedman, S.M., Uhlmann, R.F. & Cain, K.C. (1992) Physicians' attitudes toward tube feeding chronically ill nursing home patients. *J. Gen. Intern. Med.* **7**, 46–51.
Wall, M.G., Wellman, N.S., Curry, K.R. & Johnson, P.M. (1991) Feeding the terminally ill: dietitians' attitudes and beliefs. *J. Am. Diet. Assoc.* **91**, 549–552.
Wrigley (1995) Mental health legislation and the care of people with dementia. *Ir. J. Psych. Med.* **12**, 4–5.

Appendix 1

Case 1

Fiona Murphy is a 29-year-old woman in a permanent vegetative state following a road traffic accident. Her neurological status has been unchanged for over a year. The only treatment she is receiving is artificial nutrition and hydration via PEG, which replaced a nasogastric tube (initiated in the days following the accident). Her case is now being reviewed. Disregarding legal precedents, how would you feel about long-term tube feeding this patient?

Case 2

Anne McGrath is an 82-year-old woman with severe dementia and is described by nursing-home staff as totally dependant in all her activities of daily living, not recognizing nursing-home staff, occasionally smiling at the television and moaning for unclear reasons. She refuses to eat with no underlying medical or psychological cause being found. Repeated attempts of spoon feeding over a number of months have not helped and in the past 3 months she has lost 5% of her usual body weight. She has no close family and no known wishes regarding tube feeding. Would you tube feed this patient?

Case 3

Catherine O'Donnell is a 49-year-old woman with cancer of the colon with metastasis in her liver and kidney. She underwent surgery 1 year ago but this was not successful and presently has both a urostomy and colostomy. In the past 6 months she has lost 7% of her usual weight and has found it difficult to eat, complaining of reflux, flatulence, watery colostomy output and severe pains. None of your advice has helped her to gain weight.

When asked her wishes, she says to do whatever you think is best. Would you consider a naso-gastric feeding tube?

Case 4

Patricia O'Reilly is a 79-year-old woman who is in intensive care following a stroke 6 days ago. She is now suffering from oro-pharyngeal dysphagia, dysarthria, reduced cough and gag responses, right-sided hemiplegia and blurred vision. She normally resides in a nursing home and most of her family live abroad. Would you tube feed this patient?