

Should they have a percutaneous endoscopic gastrostomy? The importance of assessing decision-making capacity and the central role of a multidisciplinary team

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ABSTRACT

Decisions about percutaneous endoscopic gastrostomy (PEG) can be clinically and ethically challenging, particularly when patients lack decision-making capacity. As the age of the UK population rises, with the associated increase in prevalence of dementias and neurodegenerative diseases, it is becoming an increasingly important issue for clinicians. The recent review and subsequent withdrawal of the Liverpool Care Pathway highlighted feeding as a particular area of concern. The authors undertook a 1-year retrospective review of individuals referred to the feeding issues multidisciplinary team (FIMDT) at Addenbrooke's Hospital, Cambridge, UK, in 2011. The majority of patients referred (n=158) had a primary diagnosis of cancer (44%). The second largest group was those who had had a stroke or brain haemorrhage (13%). Twenty-eight per cent of patients had no, or uncertain, decision-making capacity on at least one occasion during decision-making. There are reflections on the role of a multidisciplinary team in the process of decision-making for these complex patients.

KEYWORDS: Percutaneous endoscopic gastrostomy, decision-making capacity, feeding issues multidisciplinary team

Introduction

Decisions about feeding interventions can be highly emotive and ethically challenging. Intervention has the potential to prolong suffering and increase morbidity, whereas non-intervention

can lead to premature death. Competing human rights, such as the right to life (European Convention on Human Rights [ECHR], Article 2) and the right to freedom from degrading treatment (ECHR, Article 3), must be measured and balanced. In the UK, the recent review and subsequent withdrawal of the Liverpool Care Pathway for the Dying has highlighted these difficulties, revealing public concern surrounding the provision and withdrawal of artificial nutrition and hydration towards the end of life.¹ Decision-making is particularly challenging if the person in question lacks decision-making capacity. In this review the authors examine the importance of assessing decision-making capacity when considering percutaneous endoscopic gastrostomy (PEG) insertion and the central role of a multidisciplinary team in the decision-making process.

Background

The term 'dysphagia' refers to difficulties with swallowing, which may occur at the oral preparatory, oral, pharyngeal or oesophageal stage.² Swallowing impairments increase with age.^{3,4} Estimates of the prevalence of dysphagia in older adults range from 15% of those living in the community³ to 40–60% of those living in a care home.⁴ Dysphagia also occurs in younger populations such as those with neurodegenerative disorders,⁵ intellectual and developmental disabilities,⁶ acquired brain injuries such as stroke⁷ and those being treated for cancer, in particular head and neck cancers.⁸ Other difficulties with eating and drinking can occur as result of psychological issues, physical restrictions, poor dentition or behavioural problems.^{4,6,9,10}

The consequences of difficulties with eating and drinking can be serious and potentially life threatening. If left unrecognised or untreated, dysphagia can lead to choking and aspiration pneumonia.^{3,4,11} Malnutrition and dehydration may also occur, which can lead to impaired immune response, reduced muscle strength and fatigue, reduced respiratory function, impaired thermoregulation, and depression and self-neglect.¹¹ People suffering from malnutrition have longer hospital stays and are more likely to be readmitted.¹² For older people, poor nutritional status carries a substantially greater risk of death and dependency.¹³

When individuals encounter difficulties with eating and drinking, or develop problems that make swallowing unsafe,

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nutrition support may be indicated. This can include: modified oral intake using thickened food and fluids; methods of artificial nutrition such as parenteral nutrition, in which nutrients are given intravenously; and enteral tube feeding, in which feed is delivered directly into the gastrointestinal tract, eg via a nasogastric (NG) tube or PEG.¹⁴ Decisions about PEG insertion can be clinically complex. There are few studies examining PEG insertion and outcome, and there is a particular dearth of studies using randomised controlled trials (RCTs) to examine outcomes.¹⁴ PEG insertions have been associated with futile procedures and significant mortality and morbidity.¹⁵ There is also a lack of evidence of benefit in certain patient groups, such as those with advanced dementia.¹⁶

When PEG is deemed clinically appropriate and patients are able to give informed consent, they decide whether to give or withhold their consent to this intervention. When individuals lack the mental capacity to participate in decisions about their own healthcare, and have no advance decisions to refuse treatment (ADRT), decision-making is more challenging. Many patients with oral feeding difficulties, who are considered for PEG, also have disorders that put them at risk of lacking decision-making capacity. One British study found that three-quarters of patients undergoing PEG insertion lack the capacity to consent to the intervention.¹⁷ A recent systematic review of artificial nutrition for those at risk of lacking capacity found that the initial trigger for starting the decision-making process is a change in the person's clinical condition, such as choking.¹⁸ However, this alone was insufficient for the complex decisions involved: when the individual lacked capacity, the overriding objective of the decision-makers was to improve the quality of life of the person lacking capacity.¹⁸

PEG and consent within England and Wales

Laws and healthcare practices concerning artificial nutrition vary internationally.¹⁸ Within England and Wales, the Mental Capacity Act (MCA) 2005 provides legal guidance on the way to proceed when patients are at risk of lacking decision-making capacity. People over the age of 16 years are presumed to be able to make their own decisions, and are found to be lacking capacity only if all practical steps have been taken to help them make a decision without success. People are considered to be lacking decision-making capacity only if they have a disorder or impairment of the brain or mind, and are unable: to understand the information relevant to the decision; to retain that information; to use or weigh that information as part of the process of making the decision; or to communicate their decision (by talking, sign language or other means). In those contexts, clinicians need to make a 'best interest' decision on behalf of the patient, taking into account the known previous views and wishes of the patient and the current opinions of the family and carers (MCA 2005). In Scotland, decision-making in this area is covered by the Adults With Incapacity (Scotland) Act 2000. Similarly, in most US jurisdictions, individuals are expected to be able to demonstrate four abilities to show decision-making capacity: appreciate the nature of their own situation and the consequences of their choices; understand the relevant information; be able to reason about potential risks and benefits; and be able to communicate a choice.¹⁹

Within England and Wales, nutrition and hydration provided by tube or drip are regarded as medical treatments, which can

be refused but not demanded, whereas the offer of oral food and fluids is part of basic care and must always be provided.²⁰ Under English law, ADRTs (previously known as 'living wills') are legally binding documents that must be followed if valid and applicable, even if death may result.²¹ Expressions of treatment preferences, which may be known as 'advance statements' or 'advance expressions of preferences', are not legally binding, but should be included in the decision-making process when assessing 'best interests'.²¹

Recognising the complexities of making decisions about PEG, the National Institute for Health and Care Excellence (NICE) recommend that all those receiving nutrition support in hospitals and the community receive coordinated care from a multidisciplinary team, which is overseen by a nutrition steering group that reports directly to the hospital trust board.¹⁴ The guidelines are not prescriptive and do not state the form that the team should take, nor who should lead it. It is estimated that only 60% of British hospitals have such a team.²²

Setting

The Addenbrooke's Hospital feeding issues multidisciplinary team (FIMDT) was established in 2006: weekly meetings are held to discuss decisions surrounding artificial nutrition as part of the wider hospital nutrition support service. The FIMDT is chaired by a consultant in palliative medicine (SG), and also comprises a consultant in gastroenterology (JW), a consultant in medicine for elderly people, speech and language therapists, dieticians, nutrition clinical nurse specialists and an endoscopy nurse. A medical member of the ward team caring for a patient attends the FIMDT meeting to present the case, including reporting on assessment of the patient's mental capacity. Before the FIMDT meeting the patient will have been assessed by a gastroenterology physician, provided with written information about the decision-making process, and about PEG if this is being considered. After discussion within the FIMDT, if further information or assessment is needed the relevant professional will review the patient and discuss with him or her and their family. A further discussion at the FIMDT may be required before a final decision is made about the most appropriate method of nutrition support.

Aims

This paper presents and reflects on an analysis of 1 year of data about referrals to the FIMDT in 2011 with regard to the primary diagnoses of individuals referred to the FIMDT and the prevalence of potential lack of decision-making capacity among those referred.

Methods

An electronic search of Addenbrooke's Hospital's computer system was undertaken for all referral requests made to the FIMDT during the year 2011. A member of the research team (GC) identified FIMDT discussion summary reports and extracted anonymised data into a form created in Microsoft Excel. Descriptive statistical analysis was undertaken using PASW Statistics 17.

Approval to undertake this study as a service evaluation was received from the chair of the Cambridge local research ethics committee. GC was granted an honorary contract with the hospital department of gastroenterology.

Results

The search located 220 FIMDT discussion summary reports, of which 13 were duplicates and one contained too few extractable data. The 206 reports included in the analysis represent 206 separate discussions held about 158 individuals and 48 re-discussions of patients previously presented. More males were discussed (118, 57%) than females (88, 43%). Patients' mean age at the time of discussion was 65 years.

Primary diagnosis

A primary diagnoses of cancer represented 70 patients (44%) and 79 discussions (38%), most being treated for head and neck cancer (47 cases, 30% of all patients) (Table 1). The second largest group was made up of individuals who had had a stroke or cerebral haemorrhage, which represented 20 patients (12.7%) and 32 discussions (13%).

Impairment or disorder in the functioning of the brain or mind

Of all referrals (n=206), 103 (65%) had not been diagnosed with any brain disorder or impairment. Fifty-five patients (35%) had been diagnosed with a condition that could impair the functioning of their brain or mind, and put them at risk of

lacking decision-making capacity. Of all separate patient cases (n=158), the largest number (28 patients, 18%) were those with an acquired brain injury such as a cerebrovascular accident, brain haemorrhage or traumatic or other brain injury. Thirteen patients (8%) had an established or suspected diagnosis of dementia. Three patients (1.2%) had an intellectual disability, three (1.2%) had multiple disorders and eight (5%) had other disorders such as delirium, depression or an eating disorder.

Decision-making capacity

Of the 158 patients referred, 85 (54%) were judged to have decision-making capacity at all meetings and 44 (28%) were assessed as lacking decision-making capacity, or having uncertain capacity on at least one occasion during the decision-making process. For 29 patients (18%) there were no statements about capacity in any of the FIMDT summary discussion reports. Of the 206 FIMDT discussion summary reports (representing the number of discussions held), decision-making capacity was assessed to be: present in 49% of individuals, absent in 26%, uncertain in 4% and in 21% there was no information about capacity assessment.

Decision-making capacity and recommendations

Of the 44 (28%) individual patients who lacked capacity or had uncertain decision-making capacity on at least one occasion

Table 1. Cross-tabulation illustrating primary diagnoses by each discussion held at feeding issues multidisciplinary team (FIMDT) meetings (n=206) and by individuals referred to the FIMDT (n=158).

Primary diagnosis	Number of discussions	Percentage of all discussions	Number of cases	Percentage of all cases
Head and neck cancer	50	24.2	47	29.7
Other cancer	29	14.1	23	14.6
Cerebrovascular accident	24	11.7	14	8.9
Brain haemorrhage (all)	8	3.9	6	3.8
Other brain injury	4	1.9	3	1.9
Road traffic accident	5	2.4	2	1.3
Locked-in syndrome	1	0.5	1	0.6
Motor neuron disease	14	6.8	13	8.2
Parkinson's disease	14	6.8	8	5.1
Other progressive neurological condition	11	5.3	6	3.8
Dementia	3	1.5	3	1.9
Cardiac condition	5	2.4	4	2.5
Pneumonia – aspiration and other	8	3.9	6	3.8
Dysphagia/other swallow issue	5	2.4	3	1.9
Down's syndrome	3	1.5	1	0.6
Learning disability	3	1.5	2	1.3
Cerebral palsy	1	0.5	1	0.6
Chronic obstructive pulmonary disease/ other respiratory condition	5	2.4	3	1.9
Anorexia nervosa	2	1.0	1	0.6
Other	11	5.3	11	7.0
Total	206	100	158	100

during the decision-making process: 15 were recommended for PEG or percutaneous endoscopic jejunostomy (PEJ) insertion; 12 required further information before a recommendation was made, or were provisionally considered dependent on changes in clinical condition; 9 were recommended for NG or nasojejunal (NJ) feeding, or were to continue with NG/NJ; 3 were potential end-of-life cases and were recommended for further discussion; 2 were recommended to optimise oral diet and intake; 1 was to continue spoon feeding; 1 was to wait for input from an independent mental capacity advocate; and 1 report had missing data.

Discussion

A significant proportion of people considered for nutrition support interventions have medical conditions with the potential to impair their decision-making capacity, or are judged to lack capacity at the time of decision-making. At the time of discussion by the FIMDT (n=206), 30% had uncertain or absent decision-making capacity, and 35% had a condition with the potential to directly affect the functioning of the brain or mind, putting them at risk of lacking decision-making capacity, such as dementia, acquired brain injury or an intellectual disability. These findings indicate a high rate of decision incapacity in those considered for feeding interventions, such as PEG. Other studies of decision-making capacity in hospital patients have found that 26% of inpatients in all wards lacked decision-making capacity.¹⁹ In comparison, a recent systematic literature review examining the prevalence of decision-making capacity found that the rate of decision incapacity in elderly general population controls was 2.8%.¹⁹

Decision-making capacity is a basic requirement for informed consent to be legally and ethically valid. Following the correct local legal procedures for assessing decision-making capacity, and following the correct processes if decision-making capacity is found to be lacking, is crucial for gastroenterologists, dieticians, speech and language therapists, and all clinicians involved with any feeding interventions, including PEG. Failure to obtain valid informed consent or to follow the MCA procedures in the event of incapacity could result in criminal or civil charges of negligence, assault or battery, dependent on the legal jurisdiction.

In the complex circumstances surrounding decisions about nutrition support, there may be competing interests and pressures, such as conflicting views between clinicians and lay carers as to what would be in the patient's best interests, or the potential proximity of the end of life and the burdens of life-limiting illness. These decisions have major implications for life expectancy and survival, and the potential to prolong suffering.

Within this example of England and Wales, the MCA 2005 lays down the principles and processes under which clinicians can proceed if an individual is found to lack the capacity to participate in decision-making: decisions must be in their best interests, extending beyond purely medical best interests to involve all relevant circumstances including the person's expressed wishes, feelings, beliefs and values, the views of others with an interest in their welfare, their carers and those appointed to act on their behalf. Multidisciplinary teams such as the FIMDT provide a forum in which key medical and social factors can be considered alongside, and in combination with,

any discussions with relatives, the treating clinical team, other relevant parties and consideration of advance directives.

In real-world clinical practice, a best interest decision for a person who lacks capacity is not a single decision point, but rather an ongoing process of discussions and decisions. A multidisciplinary team meeting in itself is not sufficient for the full best interest process under the MCA 2005. However, a multidisciplinary team meeting provides a crucial space for clinicians to come together and discuss the wider issues involved in detail and depth. Multidisciplinary team meetings may be of particular benefit to clinicians working within nutrition support, as the findings from this review indicate that a significant proportion of those referred for feeding issues are a vulnerable population: around one-third of all referrals had uncertain or absent decision-making capacity on at least one occasion during the decision-making process. A subsequent paper will report on an observational study of FIMDT discussions and decision-making, including ways of maximising decision-making capacity and challenging decisions about feeding interventions in real-world clinical practice. ■

Laws and international conventions

- > Council of Europe. Convention for the Protection of Human Rights and Fundamental Freedoms (ECHR), as amended by Protocols No. 11 and No. 14. Rome, 4. XI. 1950.
- > England and Wales. The Mental Capacity Act 2005.
- > Scotland. Adults With Incapacity (Scotland) Act 2000.

Acknowledgements

Gemma Clarke is funded by NHS Cambridgeshire Flexibility and Sustainability funding and the National Institute for Health Research, Collaboration for Leadership in Applied Health Research and Care for Cambridgeshire and Peterborough. Anthony Holland is funded by the Health Foundation. This article presents independent research supported by the National Institute for Health Research (NIHR). The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.

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