

Quality improvement report

Using rapid-cycle quality improvement methodology to reduce feeding tubes in patients with advanced dementia: before and after study

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Abstract

Problem Despite lack of evidence that enteral feeding tubes benefit patients with dementia, and often contrary to the wishes of patient and family, patients with dementia who have difficulty swallowing or reduced food intake often receive feeding tubes when hospitalised for an acute illness.

Design We conducted a retrospective chart review of all patients receiving percutaneous endoscopic gastrostomy or jejunostomy tubes between March and September 2002. QI interventions including a palliative care consulting service and educational programmes were instituted. We conducted a second chart review for all patients receiving feeding tubes between March and September 2003.

Setting 652 bed urban acute care hospital.

Key measures for improvement We measured the number of feeding tubes placed in patients with dementia, the number of feeding tubes placed in patients with dementia capable of taking food by mouth, and the number of feeding tubes placed in patients with dementia with an advance directive stating the wish to forgo artificial nutrition and hydration.

Strategies for change Medical and allied health staff received educational programmes on end of life care and on feeding management of patients with dementia. A palliative care consulting team was established.

Effects of change After the interventions, the number of feeding tubes placed in all patients and in patients with dementia was greatly reduced.

Lessons learnt Multidisciplinary involvement, including participation by the administration, was essential to effect change in practice. The intensive focus on a particular issue and rapid change led to “culture shift” within the hospital community. The need to establish unified goals of care for each patient was highlighted.

Background A growing body of research over the past decade has questioned the utility of placing feeding tubes (percutaneous endoscopic gastrostomy (PEG) or jejunostomy) in patients with advanced dementia.¹ Studies have found no evidence that feeding tubes in this population prevent aspiration,^{2,3}

prolong life,⁴⁻⁶ improve overall function,⁷ or reduce pressure sores.⁸ Additionally, the quality of life of a patient with advanced dementia can be adversely affected when a feeding tube is inserted. The patient may require wrist restraints to prevent pulling on the tube^{1,3} or may develop cellulitis at the gastrostomy site, develop decubitus ulcers,¹ be deprived of the social interaction and pleasure surrounding meals,^{9,10} and require placement in a nursing home.

Unfortunately, many doctors are unfamiliar with this literature or face barriers—attitudinal, institutional, or imposed by the healthcare industry—to applying its findings to their practice.¹¹ Thus feeding tubes are placed in patients who will not benefit from this intervention and whose quality of life in the terminal stage of their illness will be adversely affected. With the expected increase of elderly people with dementia,¹² a great change in doctors’ knowledge, attitudes, and practice is necessary to prevent even greater numbers of patients receiving this futile treatment.

Context

At Lenox Hill Hospital, a 652 bed acute care facility in New York City, a multidisciplinary group of professionals concerned about improving medical care and quality of life for patients with dementia undertook a quality improvement project to address the issue of feeding tube placement in these patients. The project was conducted under the auspices of the New York Palliative Care Quality Improvement Collaborative (PCQuIC), a multisite initiative sponsored by the United Hospital Fund, RAND Corporation, and the Washington Home Center for Palliative Care Studies, with the aim of improving palliative care services in the 23 participating healthcare institutions.¹³ Faculty at the collaborative supplied training in the “plan-do-study-act” model for improvement^{14,15} and mentoring for this project over a 10 month period from September 2002 until June 2003. The project’s core team included a geriatrician, a speech pathologist, a nurse, and an administrator. The hospital’s vice president for medical affairs served as senior leader, acting as an advocate for the project.

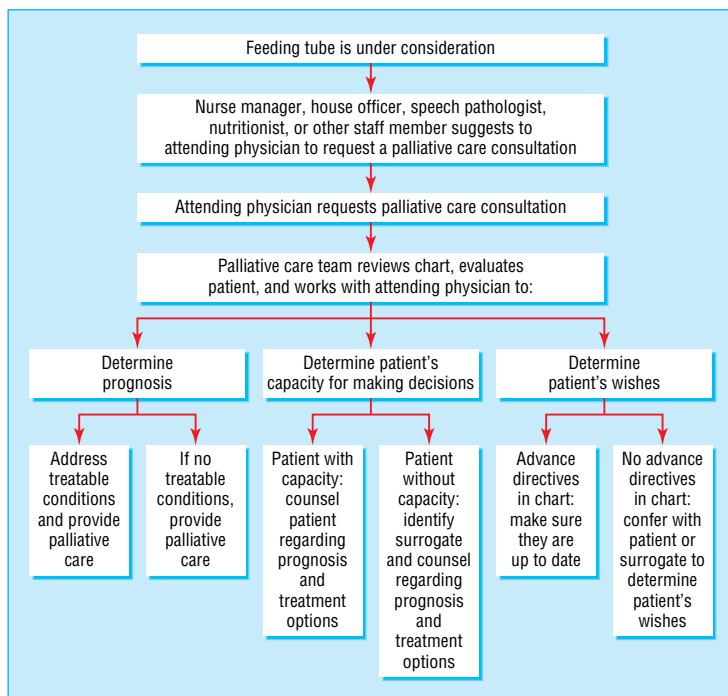
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Role of palliative care consulting team

Outline of the problem

Despite lack of evidence that feeding tube placement benefits patients with late stage dementia, despite medical risks and compromised quality of life, and sometimes contrary to the patient's advance directive, placement of feeding tubes in this population continues. We aimed to identify the extent and nature of this problem in our hospital and to intervene to change medical practice so that patients with dementia would receive medically appropriate treatment, consistent with their wishes. A retrospective chart review showed that within a six month period most feeding tubes were placed in patients with dementia. We found minimal documentation of patients' wishes regarding artificial nutrition and hydration, and few instances of formal assessment of the patients' capacity for decision making. Reversible causes for failure to eat were rarely addressed. The doctor's rationale for tube placement was documented infrequently. In cases of documented "failure to thrive," no calorie count or other assessment had been made to determine actual food intake or to assess whether it was consistent with the nutritional needs of a patient with late stage dementia. A small but important number of patients received feeding tubes despite their explicit advance directives stating the wish to forgo artificial nutrition and hydration if they were irreversibly ill and unable to make their own decisions.

Key measures for improvement

We established three aims to measure the success of our interventions:

- Reduce by 50% the number of feeding tubes placed in patients with dementia
- Reduce to zero the number of feeding tubes placed in patients with dementia who are capable of taking food by mouth
- Reduce to zero the number of feeding tubes placed in patients with dementia who have advance directives stating the wish to forgo artificial nutrition and hydration.

We hoped to achieve these aims within nine months of initiating quality improvement interventions.

Methods used to identify problems

Names of all inpatients receiving percutaneous endoscopic gastrostomy or jejunostomy in the hospital from March to September 2002 were obtained from the hospital's computer database. The core team conducted an in-depth review of the 58 available charts of the 71 patients who received tubes. Data collected included patients' characteristics, medical diagnoses, presence of dementia (either reported as a diagnosis or inferred from notes in the chart), advance directives or other evidence of the patient's wishes regarding artificial feeding, doctor's rationale for tube placement, and a detailed chronology of the patient's hospital course. We conducted a second chart review, after initiation of quality improvement interventions, on all patients who received feeding tubes for the six month period March-September 2003.

Strategy for change

Beginning in January 2003, the team formed a palliative care consulting team and instituted educational programmes.

The palliative care consulting team was led by the director of geriatrics. Working with medical residents on geriatrics rotation and the existing ethics and pain consult services, the team provided support and guidance for attending physicians (figure). A letter from the hospital's vice president for medical affairs requested attending physicians to call a member of the team whenever a feeding tube was being considered for any patient, demented or otherwise. Primary care physicians, gastroenterologists, nutritionists, nurse managers, and case managers attended in-service training sessions that explained the project and enlisted participation (boxes 1 and 2) The project was publicised at the quarterly medical staff conference and at grand rounds.

Four educational programmes were instituted. Firstly, a nationally recognised geriatrician with expertise in feeding issues in dementia gave a medical

Box 1: Specialties targeted

- Speech pathology
- Nutrition
- Gastroenterology
- Nurse managers
- Case managers
- Primary care physicians
- Hospitalists (physicians specialising in inpatient care)
- Ethics committee
- Administration

Box 2: Components of in-service training

- Review of medical literature on burdens and benefits of tube feeding in patients with dementia
- Discussion of advance directives
- Linking advanced dementia to palliative care
- Explanation of quality improvement project
- Assignment of role in project

grand rounds presentation addressing the issue of feeding tube placement. The other three programmes involved the 24 medical residents in postgraduate year 2: they have a rotation of 12 sessions of pain management consultation; participate in presenting modules of the EPEC (Education for Physicians in End of Life Care) curriculum to the remainder of the medical house staff (attendance is mandatory); and spend one month on geriatrics rotation, which includes answering all palliative care consulting requests.

Effects of change

The table shows the preliminary results. The total number of tubes inserted and the number of tubes placed in patients with dementia both decreased significantly, exceeding our first aim, but the proportion of tubes placed in patients with an advance directive refusing artificial nutrition was not significantly reduced. This finding highlights a resistance by some doctors and surrogate decision makers to withholding treatment even when the patient's wishes to withhold treatment were clear. Retrospective data on ability to take food by mouth by patients in the 2002 group was not obtainable because few had received speech pathology or geriatrics evaluations to assess their ability to eat. Of the 2003 group of eight patients with dementia who received feeding tubes, two had been determined by the speech pathologist to be able to take some nutrition by mouth, four had been seen and determined to be unable to eat, and two had not received speech pathology assessments.

Lessons learnt

Use of rapid cycle quality improvement methodology^{13 14} to change medical practice in this case was successful on many levels. The intensive educational initiative, coupled with implementation of a palliative care consulting service, brought the issue of tube

Key learning points

Despite literature questioning value of this intervention, physicians insert feeding tubes in patients with dementia

Interdisciplinary teamwork and focused educational effort can rapidly produce change in practice

Nutritionists, speech pathologists, gastroenterologists, case managers, social workers, nurses, and house staff can be targeted for education

The palliative care team works with attending physician to address prognosis, the patient's decision making capacity, the patient's wishes, and treatable causes of poor food intake

placement in patients with dementia into focus for the hospital community. Medical grand rounds and in-service training sessions were well attended. From January to September 2003, the consult team intervened on 12 feeding tube cases. It is unlikely, however, that the sharp reduction in tube placement is attributable only to the organised quality improvement interventions. During the study period, physicians, nurses, nutritionists, speech pathologists, case managers, social workers, and other clinical staff seemed to talk more, formally and informally, about feeding tubes and the wider issue of medically futile treatment, suggesting a "cultural shift" within the hospital. Staff from many disciplines took pride in the rapid, dramatic results of the project, and this increased morale and belief in the possibility of positive change within the institution. Doctors' response to the project was generally positive, although a few practitioners resented "interference" with their care of patients. More commonly, doctors were grateful for the help the consulting team offered in dealing with difficult cases. Education of house staff, in both didactic sessions and clinical rotations, was a key component in the success of the project.

We wondered if the sharp decline in feeding tube placement in patients with dementia in our hospital had been accompanied by an increase in outpatient tube placements in outpatient settings or at nearby facilities. We have joined a consortium of hospitals in New York City to address the issue on a regional basis.

Feeding tube placement before and after quality improvement interventions

Variable	March-September 2002	March-September 2003	Change in proportion (95% CI)*
No of hospital admissions	19 399	20 468	
No (%) of patients given feeding tubes	71 (0.37)	27 (1.3)	0.002 (0.001 to 0.003)
No of charts located for review	58	27	
No (%) of patients with dementia given feeding tubes	40 (69)	8 (30)	0.393 (0.145 to 0.581)
No (%) of patients with dementia and advance directive refusing artificial feeding given feeding tubes	8 (14)	4 (15)	-0.01 (-0.17 to 0.15)

*Software used: Confidence Interval Analysis, version 2.

It became clear from chart review and palliative care consultations that absence of clear goals of care often led to unnecessarily long, complicated stays in hospital, contradictions among recommendations made by various clinicians on a case, and care inconsistent with patients' wishes. The palliative care consultant became a facilitator of communication among medical staff and between doctor and patient or surrogate, to establish goals of care. We have started a new quality improvement activity for early establishment and documentation of goals of care.

Contributors: CM and EC participated in project design, data collection, data analysis, palliative care case consultations, in-service instruction, and other staff education in palliative care, and writing of this report. Julie Wityk participated in data collection and served as liaison with the PCQuIC faculty. Nancy Mooney, Tamar Kotz, and Barrie Guise participated in data collection. Walter Ettinger assisted with project design and served as the project's senior advocate within the institution. John Rapoport and Arthur Blank assisted with data analysis. CM is guarantor.

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A memorable patient

Prophets and prophecies

KS entered my clinic beaming. "Did you hear the news last month that Russia and America have dumped their nuclear weapons into the sea?"

I had. It was big news; the end of the cold war. "Was it you?" I asked.

"Of course. Russia and America realised that I am the ultimate superpower. They fired their missiles at me, which I deflected into the sea. They now claim that they willingly destroyed the weapons." His eyes twinkled, seeking my approval of his explanation, yet mocking me to defy it.

That was KS, a Punjab clerk. He had come to psychiatric outpatients at the insistence of his wife, who was fed up with repeated complaints by his colleagues. Every time KS thought they were doing something wrong, he chastised them, even handing out sentences—hell or bad karma in the next lifetime. The sentences were scribbled on a letterhead, signed "KS, God," and rubber-stamped.

He had a systematised delusional system, believing that he was all manifestations of god and had visited earth in many incarnations, including Moses, Jesus, Mohammed, Buddha, Krishna, and Nanak. He had no other symptoms of depression, mania, first rank symptoms, or organic pathology. He did not drink alcohol or take drugs and was a loving husband and father. He even had a reason for his current incarnation: "When I was Guru Gobind Singh [the 10th Sikh Guru] I ate meat. As a creator, I should not have eaten my own creation. I decided to punish myself by being born as a clerk in Punjab government."

He refused treatment ("What did you do when I was Jesus? You crucified me. What would you do to Jesus today? You would probably give me ECT.") but willingly

attended outpatients. He would state his powers, I would offer medication, we would agree to disagree, and he would promise to return. I presented him at a case conference, where we argued about the merits of treating him. There was no mental health act to guide us and neither a way nor a reason for compulsory treatment.

One day he stormed into my office unannounced and unexpected. He was visibly agitated and insisted that I stop my ongoing consultation and see him instead. I asked him to wait. Angrily he scribbled on his pad, "I hereby sentence Dr S P Singh to death," threw it at me, and stormed off. I apologised to my patient and went out to look for KS. He had gone.

His wife turned up at the next appointment. He had walked under a train. A few weeks before, the Indian prime minister had narrowly escaped an assault in Sri Lanka. KS wrote to the prime minister informing him that it was only KS's power that had saved him. On not receiving a response, KS went to meet the prime minister. He was arrested, beaten, and locked up for a few days. On release, he came to see me, the day he signed my death sentence. His wife thanked me for trying to help him.

Kierkegaard said that life can only be understood backwards. Mental health inquiries find a predictable inevitability in tragedies; if only so and so had done such and such. Living forward, the future is an endless array of unpredictable outcomes. But I still wonder. Would medication have made a difference? Would he be alive today had I seen him that day? Is this the fate of all avatars?

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