

Virtual Mentor

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Clinical Case

Helping the Patient Achieve Quality-of-Life Goals

Commentaries by Thomas Finucane, MD, Alfred Simon, PhD, and
Muriel Gillick, MD

Mrs McGoldrick was admitted to the local hospital from a local nursing home with a urinary tract infection (UTI) and multiple chronic diseases including diabetes and a history of heart attacks. Mrs McGoldrick is 81 years old, has an adult daughter, Regan, and an elderly sister, Emily. During the admission process, Mrs McGoldrick reported that she could walk only with pain and therefore spent most of her day sitting in a chair. She was evaluated by a psychiatrist immediately after admittance and was prescribed antidepressants to combat symptoms of clinical depression. She was also observed to have indications of early stage dementia.

After spending 3 days in the hospital, Mrs McGoldrick appeared to have been successfully treated for the UTI but remained weak and lethargic. In an effort to elevate her mood, the anti-depressant dosage was increased, but after several days there were no marked signs of improvement. One of the most distressing trends noted by the clinical staff was Mrs McGoldrick's intake of foods and liquids. Several tests revealed that she was suffering from hypoprotein anemia which suggested that she had not been properly nourished for a sustained period of time. The hospital staff, however, observed Mrs McGoldrick eating and drinking well when Emily fed her during one of her regular visits.

Prior to Mrs Goldrick's release from the hospital, her primary care physician, Dr Misenti, spoke privately with Mrs McGoldrick's daughter, Regan, who stated that her mother had expressed a "wish to die," believing that there was nothing more that she wanted from this life. After considering Regan's information, Dr Misenti suggested continuing the anti-depressants and giving Mrs Goldrick the option of a percutaneous endoscopic gastrostomy (PEG), which might help raise her mood and nutritional status and, hence, her quality of life. It was Dr Misenti's hope that by improving the quality of Mrs McGoldrick's life, he would also encourage her to want to live. Regan believed that this was an idea that should be explored and implemented, but Mrs McGoldrick refused to consider the option.

Commentary 1

by Thomas Finucane, MD

Mrs McGoldrick was admitted to hospital with an acute and totally reversible illness—a urinary tract infection. Once treated, she'll presumably be about as well as she was before admission. (This is in contrast to an illness like stroke, fracture or major myocardial infarction where the patient would probably not return to her previous

health state.) Her baseline functioning seems limited by chronic ambulation-related pain, and there is no evidence of recent deterioration.

During this admission, Mrs McGoldrick comes under the scrutiny of the acute medicine team, with its bias towards intervention. Had she not become infected, none of the questions now on the table would have arisen. The team notices depression, perhaps early dementia, poor food and liquid intake, and some abnormal “markers of nutritional status.” The record shows that she is not dysphagic, however, and with her sister present her oral intake is adequate and otherwise problem-free.

Mrs McGoldrick's daughter reports that her mother has expressed a wish to die. This statement of course requires that the patient be carefully evaluated for suicidal ideations. Often, however, this “wish” is presented as a fairly nonspecific expression of suffering, rather than an actual desire. In LaFontaine's *Death and the Woodcutter*, an elderly man is enveloped by hardships: hunger, exhaustion, wife, kids, debt, servitude, taxes, and soldiers. He calls on Death to come and release him. But when Death arrives and asks what he wants, he says he just needs some help moving this bundle of branches. LaFontaine concludes, “Plutot souffrir que mourir, C'est la devise humaine” [1].

PEG feeding is then suggested by the patient's primary care physician, who gives 3 reasons for his recommendations. The first is that Mrs McGoldrick's mood will improve with PEG feeding. Second, her nutritional status will be raised, “and, hence, her quality of life.” Third, with improved quality of life, the patient may be encouraged to want to live. The first issue, her mood, is discussed in an accompanying piece (see commentary by [Muriel Gillick](#)). Understanding and treating depression in dementia are very complex matters. In any case, a sick patient who's received 3 days of antidepressant medication has not been treated effectively for depressive symptoms.

What about her nutritional status and quality of life? First of all, there is a profound misunderstanding about malnutrition, and there is a vigorous promotional campaign designed to sell nutritional supplements. A human being needs calories for 3 main purposes: basal metabolism, activity, and the thermal expenditure of feeding—the energy required to digest and absorb nutrients. Basal metabolic rate depends in large part on muscle mass. If a patient is thin, slightly wasted, and sedentary, as Mrs McGoldrick is, her muscle mass will be low. Confined to bed and chair, Mrs McGoldrick's activity level is also low; she eats little; and will need only minimal energy to digest and absorb her food. In the days before PEGs, many very skinny, bedfast patients survived for years with an astonishingly small caloric intake. Lawyers and vendors of nutrition products would have us believe that such a situation is untenable.

We all want our patients to be properly nourished, but what does this mean? Although studies of feeding tubes in those with mild dementia are not available, other data show that thin patients with advanced dementia who are eating little do not live longer with PEG feeding. For a physician to tell a family member of such patients, “Well, we can either put in a feeding tube or let your mother starve to death” is both dishonest and

coercive. A truer sentence is, “Your mother is not doing well despite our best efforts. We can put in a feeding tube, but no real evidence suggests it will help her live longer, and the best evidence shows a high chance that she would die in the near future.” Similarly, no evidence whatsoever suggests that risk of infection is reduced by PEG feeding and “proper” nutrition. To the contrary, tube feeding is cited as a risk factor for pneumonia and has been shown to cause life-threatening infections of the lung, pleura, gut, peritoneum, abdominal wall, bloodstream, and more. Children with poor access to food live longer and have fewer infections when they are provided with food; adults with advanced dementia who eat little even when it is offered do not live longer, have no fewer infections, and may well have more, once PEG feeding is begun.

What do the data show about quality of life with PEG tube feeding? Most of the data concern more severely demented patients, and they are usually unable to report their inner experience. Patients who undergo PEG feeding are more likely to be restrained, which seems to contradict the suggestion that quality of life is better. But most importantly for this case, PEG feeding might reduce mealtimes with the sister—who is one of the patient's only sources of socialization—and this would be a real loss to both women. PEG might improve the quality of life for patients with severe dysphagia who cannot keep food and fluid out of the airway and who react vigorously with coughing and gagging. In general, eating is one of life's great pleasures. PEG feeding is not eating.

Finally, what is the relationship between quality of life and the desire to stay alive? LaFontaine's story refers to an important drive: the widespread and deeply held desire not to be dead. In the large, sophisticated SUPPORT initiative, quality of life had no effect on patients' desire for resuscitation [2]. Of surveyed patients with C4 quadriplegia, stable for at least 1 year, with clear cognition, 90 percent are glad to be alive [3]. This desire not to be dead is often underestimated by physicians and family members.

In conclusion, there is no physiologic basis for placing a feeding tube in this patient. She has been stable in the nursing home and should recover completely from her acute illness. She is able to protect her airway and when her sister is present, Mrs McGoldrick's intake is adequate. Tube feeding will not solve any of the problems for which it is proposed; imprecise references to “proper nutrition” should be clarified explicitly.

Beyond the uncertain and, frankly, unlikely medical benefit, an even stronger reason not to place a feeding tube exists. In many ethical decisions near the end of life, tension develops between 2 fundamental values. On one hand is reverence for life. The value of human life is the North Star by which ethical decision making should steer. On the other hand is the basic human right to say, “Keep your hands off of me,” which our patient has already expressed. Unless we are willing to counter that she is incapable of realizing the consequences of this decision, and to deprive her of her basic right to control her own body, placing a PEG would be assault. This would be

true even if PEG feeding were life-sustaining, which it is not. To undertake this intrusion based on someone else's assessment of her quality of life is simply untenable.

My approach to this patient would be to discontinue all medications that might interfere with appetite or attentiveness, including cholinesterase inhibitors, bisphosphonates, nonsteroidal anti-inflammatories, sedatives, narcotics, and many others. She should be formally evaluated for major depression. If this diagnosis is established, she should be properly treated. Meals and mealtimes should be attractive, pleasant experiences with the nursing home staff and family spending meaningful time helping Mrs McGoldrick to take nourishment. Truly caring for the patient is at the heart of good care for so vulnerable and frail a person.

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Commentary 2

by Alfred Simon, PhD

In order to justify any medical intervention, eg, placing a feeding tube as in this case, there must be *medical indication* for the treatment and the *consent of the appropriately informed patient*.

Medical indication is decisive in determining the clinical foundation for the intervention, ie, whether it should be offered to the patient at all. A physician determines whether a treatment is indicated based on his or her *medical knowledge* of the course of a disease and the effects of certain interventions on that course. Indication also depends on the physician's knowledge of the *diagnosis and prognosis* specific to this individual patient and on the *aim of treatment*. Finally, the physician must consider whether the expected benefit is in due proportion to the harm that may be expected. If a measure has little or no benefit for the patient or if the benefit causes disproportionate risk of harm, the measure has to be considered *medically futile* and should not be offered to the patient.

The fact that an intervention is medically indicated, however, does not mean that the physician is automatically authorized to carry it out. It is not the physician but rather the patient who decides on the implementation of a measure because patients with decision-making capacity have the *right to self-determination*. If a patient refuses or withdraws consent after learning about both the benefits and the risks, treatment is

not justifiable. The prerequisites for providing informed consent are decision-making capacity and appropriate *patient information*. If the patient does not have decision-making capacity, the physician should ask whether he has given his opinion on the situation at an earlier date when he was determined to be of adequately sound mind, perhaps in the form of a living will. If this is not the case, the patient's interests must be represented by a proxy or “surrogate” decision maker or, if this is an emergency situation, by the physician himself.

Application to the Present Case

The first question the physician should ask himself is whether Mrs McGoldrick presently has *decision-making capacity*. If she does, he should offer her the opportunity to reconsider her decision against a PEG; coercion and, especially, treatment of the patient against her will would interfere with her right to self-determination and would therefore be ethically unacceptable. Whether Mrs McGoldrick has decision-making capacity cannot be answered definitively based on the information presented in this case. Her age, treatment with antidepressants, and early stage of dementia do not exclude decision-making capacity but do require the medical staff to be aware of possible compromised decision making. The determination of her competence must also consider whether she is presently capable of understanding the consequences of her refusal for additional treatment. To decide this, it might be helpful to investigate whether the refusal of the treatment is *authentic*— in other words, consistent with her other known values and goals. If the physician has any doubts regarding Mrs McGoldrick's decision-making capacity, he should consult a psychiatrist.

The aim of the proposed procedure is to raise the patient's mood and nutritional status and hence, her quality of life. Yet it is questionable whether a PEG is a suitable means to this end. The fact that Mrs McGoldrick eats and drinks sufficiently when fed by her sister suggests that her insufficient nutritional status has a social and caregiving explanation rather than a medical basis. The staff at the local nursing home probably does not have enough time to feed Mrs McGoldrick, and this further perpetuates her social isolation. Maybe the food is not presented in an appealing way (eg, big portions) or Mrs McGoldrick finds this previously shared time very lonely. Instead of considering PEG, those in charge should first try to improve the social situation and nursing care of Mrs McGoldrick through greater involvement of her older sister and her daughter.

The other rationale offered for inserting the PEG is that artificial feeding would counteract imminent malnutrition and thus contribute to life extension. Without improving the social and caregiving situation, this seems to be a futile goal, since Mrs McGoldrick has made it clear—explicitly to her daughter and implicitly by refusing to eat and drink—that she does not want to live that way.

Conclusion

Application of PEG in this case seems to be *neither medically reasonable nor in the patient's best interest*. PEG is not an appropriate means for solving social or caregiving deficits. Should it not be possible to improve Mrs McGoldrick's quality of life by social and caregiving measures, it seems to make little sense to extend the situation artificially by

PEG since the patient herself obviously does not wish for this lifestyle. Apart from the questionable medical indication, Mrs McGoldrick's refusal to even discuss the possibility of PEG clearly speaks against taking this measure. If Mrs McGoldrick is still able to grasp the consequences of her decision, and is determined to have decision-making capability, her refusal is binding for the physician. If she is deemed to lack decision-making capacity, her refusal would at least be an important indicator that PEG was not her preference, which is supported by her refusal to eat and her earlier statements to her daughter, and should be taken into account by surrogates and physicians when making treatment decisions.

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Commentary 3

by Muriel Gillick, MD

The case of Mrs McGoldrick stimulates us to think about the meaning of patient autonomy for a patient with cognitive impairment and about how surrogate decision makers should evaluate quality of life. Before we consider the ethical dimensions of the case, however, we must consider the medical aspects.

The first area that should be addressed is Mrs McGoldrick's physical pain. We are told that her pain is severe enough to prevent her from walking and to confine her to a chair. It is essential to try to establish the etiology of the pain and to treat it vigorously. Pain control is the foundation of good palliative care, and lack of treatment may be at the heart of the patient's depressive symptoms and apparent lack of interest in life [1].

The second domain that requires further exploration is Mrs McGoldrick's depression. She was started on antidepressants at the time of admission to the hospital, and, when she remained weak and lethargic after 3 days, the dose was increased. Tricyclic antidepressants take 4-6 weeks to become effective; selective serotonin reuptake inhibitors typically require 2 weeks, and, while we are not told what medication is prescribed, almost all take longer than 3 days to work. If Mrs McGoldrick's depression is contributing to her anorexia, then she should probably be treated with a stimulant such as methylphenidate. The dose can be increased rapidly, and, if the patient continues to have depression with life-threatening consequences, electroconvulsive therapy should be considered.

Third, the question of dementia ought to be further pursued. We are told that Mrs McGoldrick has early dementia and, while truly reversible dementia is rare, it is important to rule out hypothyroidism and, especially in view of the patient's poor nutrition, pernicious anemia. If Mrs McGoldrick has mild Alzheimer's disease, treatment with Donepezil should be considered. Although controversy persists over whether anti-cholinesterase inhibitors produce clinically meaningful benefits, if they have any role, it is in the early stages of Alzheimer's [2].

Finally, Mrs McGoldrick's nutritional status warrants further examination. Her physician states that improved nutrition, delivered through a gastrostomy tube, will improve her quality of life and mood. While this assertion is intuitively appealing, there is little data to support the beneficial effect of artificial nutrition in the frail elderly: in a community study of 150 older individuals who received gastrostomy tubes, there was no improvement in health-related quality of life among those who survived more than 60 days [3]. In the same study, there was no change in depression scores or functional status which might contribute to quality of life. Drawing inferences about the effects of gastrostomy tubes on quality of life from our intuition has proved hazardous in other, clinically distinct, situations such as that of patients with advanced dementia. In this setting, feeding tubes are often presumed to enhance quality of life by preventing aspiration pneumonia, improving function, and decreasing pressure ulcers, but in fact they have not been proven to reliably achieve any of these surrogate markers [4]. While the role of artificial nutrition remains controversial, the only circumstances where there is consensus regarding benefit are isolated dysphagia and other non-progressive conditions that Mrs McGoldrick does not manifest [5]. The physician's suggestion that artificial nutrition would likely benefit Mrs McGoldrick also fails to take into consideration such adverse consequences of a gastrostomy tube: diarrhea, infection, and the need for restraints if the patient tries to pull out the tube.

If, after the caregiving team responds to these unresolved medical problems, Mrs McGoldrick continues to eat poorly and to express the wish to die, it is time to grapple with the ethical issues. Can the patient be compelled to accept a potentially life-saving intervention against her will? To answer this question, we must first ascertain whether Mrs McGoldrick has decision-making capacity. The fact that she has mild cognitive impairment—assuming she has early dementia rather than delirium from her infection—does not necessarily mean that she is incapable of making decisions about a gastrostomy tube. She needs to be able to communicate her understanding of the nature of the proposed procedure, the alternatives to the procedure, and the consequences of both inserting and not inserting a gastrostomy tube [6]. We do not have sufficient information about Mrs McGoldrick to know whether she meets this standard. The effect of her depression on her ability to make decisions is also a concern. The presence of depression, however, does not automatically deprive a person of the ability to participate in his or her own medical care [7].

Let us suppose that Mrs McGoldrick has had her pain and depression vigorously and successfully addressed. Let us suppose, in addition, that her primary care physician and the consulting psychiatrist assess her to be incapable of making life and death decisions. When she is told that she might feel better—and feel differently about living longer—if she had a feeding tube, she just repeats that she doesn't want it and she does not seem to be able to process the possibility that she might have a new attitude towards life if her nutrition were improved (a claim which, as mentioned above, is entirely speculative and not grounded in any persuasive data). Under these circumstances can a surrogate decision maker authorize the intervention against her will?

One standard for determining whether a surrogate can demand an intervention that the patient opposes is a *sliding scale* of decision-making capacity [8]. We commonly accept that a patient may refuse to have her blood drawn, even if she fails to fully understand the benefits of the test, because she does grasp its burdens and, at the same time, the test is very unlikely to be a matter of life and death. We also acknowledge that when a patient who is deemed incapable of making his own medical decisions and says he does not want a surgical intervention, but fails to understand that he will die without it, his decision can be overridden by his surrogate (assuming that the patient, when decision-capable, did not decline life-prolonging medical treatment). In the case of Mrs McGoldrick, who says she doesn't want a gastrostomy tube but may not fully appreciate the consequences of the choice, the ultimate decision may be left to a surrogate if it has been formally established that the patient lacks the capacity to make her own decisions. The actual benefits of artificial nutrition are not well-established, the burdens are significant, and, most importantly, there is a less invasive alternative: the patient's sister, who has been successful in feeding her or coaxing her to eat, can be asked to play a more active role in her care. The patient's daughter can be recruited to share in caregiving tasks by visiting more regularly and providing greater support. The medical profession is often eager to find a quick fix; this is a situation that will take time to sort out. As Mrs McGoldrick's depressive symptoms improve, as her pain resolves, as she engages in life review with a social worker or a chaplain, and as she spends more time socializing with her family—and eating as she socializes—perhaps her assessment of her quality of life will change. The medical team and Mrs McGoldrick's family must avoid “conflating...the meaning of caring for the patient with the provision of a feeding tube” [9].

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