Analysis and comment

Controversy

Tube feeding in advanced dementia: the metabolic perspective

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Problems with the procedure do not fully explain its ineffectiveness

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BMJ 2006;333:1214-5

Questions about tube feeding in advanced dementia continue to bedevil doctors, surrogate decision makers, and administrators and stimulate research, topic reviews, and position papers.¹⁻⁵ This article shows that the dilemma of whether or not to tube feed an incompetent, demented patient can always be clarified, and often resolved, by applying the principles of nutritional physiology. The concepts described in this article have not previously appeared in the literature dealing with the artificial feeding of incompetent patients.

Physiological homeostasis or progressive starvation?

Reduced food intake and weight loss are normal features of advancing old age.⁶⁻⁷ Food intake by elderly people may also be pathologically curtailed by factors such as ill fitting dentures, functional disability, depression, isolation, and poverty. There is increasing evidence that non-demented, elderly malnourished people benefit from nutritional supplements.⁸ To my knowledge, no randomised clinical trials have been carried out in tube fed, severely demented patients,⁹ but observational data and the results of trials of tube feeding in other conditions have led to a consensus of expert opinion that tube feeding patients with advanced dementia neither prolongs their life nor improves its quality.¹⁻³⁻⁵⁻⁹⁻¹² Why would this be so?

Tube feeding shortens the life of some patients, and it is often inefficient at delivering food.⁴⁻⁵⁻⁹⁻¹⁰⁻¹²⁻¹³ But problems with the procedure do not fully explain its ineffectiveness. Severely demented patients usually fail to benefit from tube feeding for two main reasons: they lack the potential for physical or neurological rehabilitation, and they are not starving. People who reach the advanced stage of dementia when food intake is curtailed have a low metabolic rate. Their resting metabolic rate is low because muscle wasting has shrunk their lean body mass and their brains are atrophic; their metabolic rate above basal is low because they are physically inactive. Finally, they have a history of weight loss, which the body adapts to by reducing its metabolic rate and retaining dietary protein more efficiently. This adapted state can persist indefinitely.¹⁴ Severely demented people may be thin and eat less food than

Elderly demented patients often eat enough for their diminished energy requirements

seems appropriate to their physically active (and not infrequently overweight) doctors, nurses, and surrogate decision makers; but in many if not most cases they are not progressively starving. They are in a state of physiological homeostasis.

The best evidence supporting this concept is the clinical experience that tube feeding severely demented patients fails to prevent death or improve quality of life. More specific evidence emerges from a study in which hospitalised, demented patients were found to have a history of weight loss before admission, low resting metabolic rate, and a constant body weight over a prolonged period of observation.¹⁵ These people were not progressively starving; they lived in a condition of metabolic homeostasis characterised by a low metabolic rate, low energy consumption, and constant body weight without apparent detriment.

Doctors can readily determine which of their patients are progressively starving by weighing them. In advanced dementia, a constant body weight, even if subnormal, rules out progressive starvation and eliminates any medical indication for tube feeding. There is no physiological reason nor any medical evidence to presume that a medically stable, severely demented person whose body mass index exceeds 18.5 is at high enough risk of the complications of malnutrition to

justify the indignity, discomfort, and danger of tube feeding.^{14 16} Indeed, a body mass index as low as 17 can be tolerated without discomfort by young adults.¹⁴ It is also possible for weight loss to occur but be physiologically inconsequential. A person who has lost 1 kg over four weeks will have sustained an average daily energy balance of -285 kcal/day (1193 MJ). (Adipose tissue, which is 85% fat, accounts for most of the endogenous energy store consumed. The energy balance is calculated as $-850 \text{ g fat} \times 9.4 \text{ kcal/g fat} = -7990 \text{ kcal/28 days} = -285 \text{ kcal/day}$.) An energy deficit this small could be eliminated by attention to the way food is selected, prepared, and presented.^{1 9 11 12 17} The energy imbalance may correct itself: more weight loss may induce lowering of the metabolic rate sufficient to restore energy equilibrium.

The moral argument

Patient autonomy should be considered from the metabolic perspective. No person's preferences, especially ones as primal as when, what, and how much to eat, should be over-ridden without convincing justification.^{10 13} Correctable reasons for reduced food intake, such as depression, ill fitting dentures, and poor quality or presentation of food, should be dealt with. Patients with dysphagia may eat more food if the characteristics of their diet are modified. But once these issues have been addressed as well as possible, it is legitimate to conclude that a person who chooses to consume amounts of food that are sufficient to maintain constant body weight is showing personal preference and, arguably, sound judgment. An important caveat is vitamin deficiency. Folic acid deficiency, Wernicke's encephalopathy, and scurvy are underdiagnosed in patients with terminal diseases like advanced dementia, and are easily prevented by providing a daily multi-vitamin.

The moral argument for tube feeding is that it is wrong to deny a person ordinary nutritional sustenance.^{2 4 5 11 17} A patient who shows a strong desire to eat but cannot be allowed to eat by mouth for mechanical or safety reasons is a candidate for tube feeding. In some patients the weight loss profile indicates that, without tube feeding, death by starvation is inevitable.¹¹ But the moral argument for tube feeding does not apply to the severely demented person who merely indicates a disinclination to eat much food and whose weight remains constant or nearly so.

In some cases family members may insist that a demented person is not eating enough, even though constant body weight proves the contrary. Tube feeding may be so deeply rooted in cultural norms, or so psychologically rewarding to the surrogate decision maker, that it is implemented for what are essentially cosmetic reasons. In difficult and uncertain situations the astute clinician can proceed in a way that respects the family while minimising the adverse effects and dangers of tube feeding, by limiting forced feeding to the minimum amount that prevents weight loss, and withdrawing it promptly if an adverse event occurs.¹⁸

Should formal clinical trials of tube feeding be carried out in severe dementia? Perhaps, but proper evidence based medicine requires attention to the design of trials. Given the failure of existing practice guidelines to explicitly define what it is that is being

Summary points

Patients with advanced dementia should be weighed at four week intervals

Constant body weight rules out starvation even if the patient is disinclined to eat what seems to be an adequate amount of food

Medically stable patients who lose weight require attention to the characteristics, quality, and presentation of their food

A patient who continues to lose weight despite optimisation of the diet but whose body mass index remains greater than 18.5 is more likely to be harmed than helped by tube feeding

treated, it may be all right that randomised clinical trials of tube feeding severely demented patient have not yet been carried out. A clinical trial whose design ignores the physiological principles explained in this article—and they are ignored in current practice guidelines and much of standard clinical care—would be scientifically invalid.

Contributors and sources: LJH is an internist on the nutritional support team of a university hospital, and an investigator in the field of protein and energy metabolism.

Funding: The preparation of this article was supported by Grant MOP-8725 from the Canadian Institutes of Health Research.

Competing interests: None declared.

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(Accepted 10 October 2006)

doi 10.1136/bmj.39021.785197.47