

Case report

Feeding at the end of life in sub-Saharan Africa, when less is more



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Abstract

Nutrition remains key in care for patients with any medical illness. Decision to alter or stop nutrition at the end of life or when a patient is suffering from a chronic life limiting illnesses can be challenging for both patients, their families and medical providers. Nutrition guidelines that specifically cater the population in sub-Saharan Africa are lacking to help guide decisions making especially at the end of life.

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Introduction

Nutrition remains a key part of medical care and often seen by many as akin to preserving life. Artificial nutrition is considered a medical intervention aimed to help provide food and water to patients who are unable to orally consume any. Choosing not to initiate nutrition or stopping it when patients are suffering from chronic life limiting illness can be a difficult decision for both family members and the health care providers. These decisions can be ethically challenging especially in low to middle income countries like Kenya, that do not have the educational infrastructure, policies and guidelines on the use and boundaries of artificial nutrition. We present such a case.

Patient and observation

Mr. Ray, a 74 years old male, suffering from hypertension presented to our institution after having suffered a major stroke. Prior to his stroke, he lived a full life with his wife, Ms. Jane, for over fifty years in Kenya. His stroke had left him fully dependent on Jane for his activities of daily living. He was unable to speak, move or swallow.

Mr. Ray's medical course, since his stroke, had been challenging requiring Ms. Jane to make key decisions about his care. Providing nutrition to Mr. Ray had been complicated by many failed attempts at placing a gastrostomy (PEG) tube due to previous surgeries and his abdominal anatomy. His wife eventually opted for a nasogastric tube to help provide nutrition and medications. After a long stay in the hospital, we were finally able to help her arrange for medical care at their home located in a rather remote part of Kenya. It was strongly felt that Ray would be much more comfortable at home.

Over the course of many months, Mr. Ray's quality of life gradually and progressively declined. He required multiple

admissions to the hospital due to various stroke-related complications including pneumonias and urinary tract infections. Changing his nasogastric tube required advanced planning and coordination. His wife slowly grew to resent the procedure as advancing the nasogastric tube caused Mr. Ray much discomfort. Ms. Jane has grown visibly exhausted, often crying and unable to make decisions, clearly suffering from caregiver burnout. Counselling over the phone seemed to help only somewhat.

Eight months after his stroke, when Mr. Ray's nasogastric tube failed again, his wife decided to bring him to our facility. His condition has deteriorated to the point that he made no purposeful movement and only voiced intermittent groans when turned. After much discussion with Ms. Jane and her daughters who lived abroad, a decision was reached to not replace the nasogastric tube. The daughter could not bear to see their father in such a desperate condition and for them, the thought of causing their father repeated distress by replacing the nasogastric tube was too much to bear and something he would not have chosen for himself. Total parental nutrition was also deferred as this did not add to his quality of life. This decision by the family was ethically bothersome to some of the physicians and nurses taking care of him because it implied that the patient was being starved to death.

Discussion

Dysphagia remains a common complication of stroke. The reported incidence rates range widely between 37% to 78%, due to the variation in definition and assessment of dysphagia, timing of examination and patient selection [1,2]. The presence of dysphagia has been associated with increased risk for aspiration pneumonia and mortality [1,3]. Severe dysphagia is a strong predictor of unfavorable outcomes and confers an 8.5 fold higher risk of death compared to patients with normal

swallowing processes [2]. The presence of dysphagia has also been associated with malnutrition, dehydration and increased length of hospital stay [2,4].

There are various methods to provide enteral feeding to stroke patients who suffer from dysphagia. Enteral feeding can be provided via a nasogastric tube (NGT) or percutaneous endoscopic gastrostomy (PEG). Each method has its pros and cons and needs to be weighed along with the patient's wishes and eventual outcome. The FOOD Trial showed that PEG feeding was associated with an increase in the risk of poor outcomes and death compared to NGT feeding [5]. Conversely, Hamidon *et al.* in their study showed that PEG feeding was more effective than NGT feeding as the latter reduced the nutritional status of the patients in their study group [6]. In contrast, Oundi and colleagues in their recent study showed that patients who received direct enteral tubes such as gastrostomy or jejunostomy, compared to a NGT after suffering a stroke, had more severe disability at discharge and were associated with higher rates of institutionalization, medical complication and long-term mortality [7].

Retrospective studies by Wilmskoetter and colleagues showed that stroke patients with a PEG tube were twice as likely to be readmitted within 30 days when compared to stroke patients without a PEG tube. A PEG tube was an independent predictor for all-cause unplanned hospital readmission 1 year post placement. Furthermore, readmissions were linked to complications from the PEG tube [8,9].

In fact, there is little evidence that artificial nutrition improves the quality of life in patients with chronic life limiting illnesses. Many physicians are ill informed on the implications of providing artificial nutrition, often unaware of the evidence and over-estimating positive outcomes for their patient populations [10]. This is also true for families whose expectations about artificial nutrition are often contradicted by clinical outcomes of the patient [11].

Nutrition remains a key part of health and vitality. Discontinuation, even in the setting of poor overall prognosis, can be a difficult decision for the patient's family and the medical team taking care of the patient. In the US and Western Europe, the role of artificial nutrition has been debated since the 1980s. The laws in many US states assert that artificial nutrition is akin to medical treatment, and can be withheld or withdrawn by surrogate decision makers if it is against the patient's wishes and interest [12,13]. In addition, surrogates can use substituted judgment to make such decisions if it is felt to be in line with the patient's best interest.

It is known that during end of life, patients usually have no appetite and as the body begins to shut down, nutritional need decrease dramatically [14]. Families fear that denying or stopping artificial feeding will hasten death. In fact, it has been shown that continuous feeding provides resources that the body can no longer accommodate, causing burdensome symptoms and patient discomfort [14,15]. With its attendant complications, artificial nutrition in specific patients especially with life limiting conditions, can be detrimental to the overall health and quality of life.

Unfortunately, not much is known or has been published on how culture in sub Saharan Africa influences choices on artificial nutrition. From our anecdotal experience, food and water is key in preserving life and most Kenyans often prefer to continue with feeding, either via NGT or PEG, to help preserve life and avoid starvation, even when their loved ones suffer from chronic life limiting illnesses. Most medical providers also feel that nutrition remains keys in preserving life and denying one food or water is akin to starvation.

Mr. Ray and Ms. Jane's story illustrates the difficult decisions that surround artificial nutrition in patients with catastrophic neurologic injury and resulting long-term dysphagia. Education on best practices regarding artificial nutrition in patients with progressive terminal medical conditions can help

alleviate the anxiety and stigma attached to treating artificial food and hydration as a medical intervention, which, may no longer be indicated in certain patients.

Discontinuing or not initiating artificial nutrition even in patients with poor chances of meaningful recovery and progressive illness is fraught with cultural and emotional implications. In sub-Saharan Africa, developing policies and guidelines that reflect the current evidence, could help take some of the burden off the shoulders of families and other decision makers and perhaps ease the discomfort of health care providers in regards to discussing artificial nutrition in patients with chronic life limiting illnesses. We also need to better understand how cultures influence such decisions especially in this sub-Saharan Africa.

Conclusion

The family decided against a NGT. Mr. Ray was eventually discharged home with sublingual and rectal medications to ensure that any anticipated symptoms were adequately addressed. He remained comfortable at home surrounded by his loved one. He passed away four days later.

Competing interests

The authors declare no competing interests.

Authors' contributions

All authors contributed to this work. All author have read and agreed to the final manuscript.

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