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Nutrition, older people and the end of life

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ABSTRACT – Older patients are at increased risk of malnutrition, resulting in higher mortality and morbidity. It is important to address nutritional need early in order to prevent or mitigate these adverse outcomes. Decisions about nutrition and hydration for older people presenting with acute illness or evolving multiple long-term conditions present great difficulty to all involved. Clinicians are more likely to encounter such situations as the population of older people with frailty syndromes expands. The clinical evidence base to guide such decisions is sparse and largely unhelpful. Clinicians must recognise their role in these difficult decisions. In addition to familiarity with the clinical evidence base, they must be fully informed of the legal, professional and moral context of the decisions with which they are faced. Responsible clinicians have a professional duty to elicit, understand and weigh the views of their patient, and where necessary their representatives. This can only be undertaken through a process of facilitated patient choice utilising the available legal and professional decision-making frameworks. Any decision relating to clinically assisted nutrition and/or hydration in a frail older person who is considered to be nearing the end of their life must also include explicit consideration of the needs of that individual for formalised palliative care.

KEY WORDS: Nutrition, frailty, malnutrition, multi morbidity, end-of-life care

Introduction

Decisions about nutrition and hydration for older people presenting with acute illness or evolving multiple long-term conditions present great difficulty to all involved in caring for these individuals. Clinicians are more likely to encounter such situations as the population of older people with frailty syndromes expands. The clinical evidence base to guide such decisions is sparse and largely unhelpful. Clinicians must recognise their role in these difficult decisions and, in addition to clinical evidence, they must be fully informed of the legal, professional and moral context of the decisions with which they are faced.

In 2011 the Care Quality Commission (CQC) inspected 100 NHS hospitals with regard to dignity and nutrition in older people. Two standards were assessed: [1]

1 Were patients shown respect?
2 Were patients given enough food and water?

The CQC reported that 45 hospitals met both standards, with a further 35 meeting at least one standard, but with improvements suggested.[1] Twenty hospitals failed either one or both standards. Issues highlighted included patients not being offered adequate help to eat and being prevented from completing meals due to interuptions.[1] These aspects of inadequate care were also highlighted in the Mid-Staffordshire NHS Foundation Trust Public Enquiry.[2,3] Robert Francis QC concluded that there was a failure to meet the challenge of the care for older people through provision of an adequate professional resource and that some of inadequate treatment could be characterised as 'abuse of vulnerable persons'. In his 2013 report recommendations about provision of food and drink in the elderly were specifically mentioned:[3]

The arrangements and best practice for providing food and drink to elderly patients require constant review, monitoring and implementation.

The vulnerable older adult

By 2034 the number of people in the UK over the age of 85 years will be 2.5 times greater than in 2009, reaching 3.5 million, accounting for 5% of the population.[4] One of the most important challenges that the NHS faces is caring for the expanding population of frail older people and addressing their complex medical needs. This population includes vulnerable adults and has a high prevalence of multiple long-term conditions (LTCs), disability and care dependencies.

Age is a significant factor in the prevalence and incidence of LTCs; 14% of those under the age of 40 years report one LTC, rising to 58% of those over the age of 60 years. Nearly half of those aged over 80 years have three or more LTCs.[4] Multiple LTCs are an independent risk factor for adverse outcomes, in particular creating excess risk of disability and mortality over and above that attributed to individual diseases.[5] People with LTCs place high demands on healthcare resources. They account for 70% of all inpatient bed days, 64% of outpatient appointments and 50% of GP consultations (*General lifestyle survey*).[4] Around 70% of the total health and care spend in England is attributed to caring for people with LTCs, which means 30% of the population accounts for 70% of the spend.[6]

Patients with one or more LTCs face increasingly fragmented and single disease specific responses, despite their wish for a holistic approach.[6] Loss of patient centricity may be compounded by the use of the term co-morbidity, where a single disease assumes a central place, as highlighted in Feinstein's definition:[7]

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Any distinct additional clinical entity that has existed or may occur during the clinical course of a patient who has the index disease under study.

When considering multiple LTCs the term 'multimorbidity' is preferable, defined as the coexistence of two or more chronic conditions, where one is not necessarily more central than the others. This terminology captures multiple conditions including those that are highly prevalent (heart disease, diabetes, arthritis), but extends to less common conditions, for example musculoskeletal injury.[7] The concept recognises that highly prevalent conditions co-occur frequently and that the pathophysiology of these diseases may overlap, creating coexistent but not necessarily co-dependent conditions. This holistic view allows a more patient-centred approach in addressing multiple LTCs.[7]

LTCs can contribute to the development of frailty which exhibits an exponential increase in prevalence with advancing age.[8] Two people with the same chronological age can vary greatly in their health and functional status[9] and, although many older people are frail, it is not an inevitable part of ageing.[10] Fried has defined a frailty phenotype focusing on physical demise.[11]

Collard's study of 61,500 subjects found that, according to their criteria, 10.7% of community-dwelling older people exhibit frailty; frailty increased with age and was more common in women.[9] They suggested that a person becomes frail when they are compromised by a decline in their reserve capacity across multiple physiological systems. This compromises the patient's ability to withstand small physiological disturbances, leading to adverse outcomes such as functional decline, institutionalisation and death.[12]

Although frailty does not have a precise definition, there is general agreement that it reflects a vulnerability to adverse health outcomes. It is a complex biological, social and psychological syndrome that is distinct from, but overlaps with, multimorbidty.[13] Importantly the terminology highlights an increased disease burden and demand for healthcare resource.

Malnutrition in elderly people

Malnutrition, a state in which a deficiency of nutrients causes measurable adverse effects on body composition, functional or clinical outcome,[14] affects approximately one in three patients admitted to hospital or care homes.[15] It has been estimated that malnutrition affects up to three million people in the UK, accounting for up to £13 billion a year of public expenditure. Pichard[16] suggests that its prevalence in hospitals is approximately 46%, rising to 50% in people over the age of 60 years and 77% of those over the age of 80 years.[16]

One criterion common to frailty measures is unintentional loss of weight. Ageing is associated with physiological, psychological and social changes, which may affect food intake and body weight. Older people suffer from malnutrition more commonly and their nutritional status may deteriorate more quickly during acute illness from which recovery is more difficult.[17]

There are many proposed mechanisms of unplanned weight loss during hospital admission. Nutritional intake may decline due to issues with physical access to food or dislike of the choices available. Acute illness and surgery increase nutritional demands and can physically impair eating or induce poor appetite. Unplanned weight loss leads to malnutrition and adverse health outcomes, such as delayed wound healing, surgical complication and impaired immunity. It is associated with increased length of hospital stay. Despite this it remains largely unrecognised and persists without appropriate advice and intervention due to a lack of training and understanding among health professionals.[15]

The National Institute for Health and Care Excellence (NICE) offers best practice guidance on the care of adults who are malnourished or at risk. They suggest that all hospital inpatients on admission and all outpatients at their first clinic appointment should be screened to assess nutrition. This should be repeated weekly for inpatients and when there is clinical concern for outpatients. People in care homes should be screened on admission and when there is clinical concern. Those who are classified as malnourished or at risk of malnutrition require nutritional support.[14]

Malnutrition is defined as:[14]

- a body mass index (BMI) of <18.5 kg/m^2
- unintentional weight loss of >10% within the last 3–6 months
- a BMI of <20 kg/m^2 and unintentional weight loss of >5% within the last 3–6 months.

People at risk of malnutrition are identified as having either:[14]

- eaten little or nothing for >5 days and/or are likely to eat little or nothing for ≥5 days
- a poor absorptive capacity and/or high nutrient losses and/or increased nutritional needs from causes such as catabolism.

Nutritional support suggested by NICE includes:[14]

- oral nutrition support: fortified food, additional snacks and sip feeds
- enteral tube feeding: the delivery of a nutritionally complete feed directly into the gut via a tube – nasogastric (NG), percutaneous endoscopic gastrostomy (PEG) or radiologically inserted gastrostomy (RIG)
- parenteral nutrition: the delivery of nutrition intravenously.

When using clinical interventions valid consent must be gained. It is essential to act within relevant consent law, as set out (for example) in the Mental Capacity Act (England and Wales) or the Adults with Incapacity Act (Scotland) to assess for decision-specific capacity. For those without mental capacity, decisions about nutritional intervention must be made in their best interests, based on an assessment of the overall benefits of proposed interventions.[18,19]

Clinical evidence for benefit from nutritional intervention

Assessment of overall benefit based purely on clinical evidence is, however, problematic. A 2011 Cochrane review, focused on

the effects of oral dietary supplements in elderly patients, concluded that evidence for the efficacy of oral supplementation is limited. It concluded that supplementation produced a small but consistent weight gain in elderly patients, but did not provide any significant survival benefit.[15] Baldwin *et al* in 2011 published a review on dietary advice for illness-related malnutrition in adults of all ages, which included 36 studies with 2,714 randomised participants.[15] Again no significant improvement in mortality was identified. These findings are supported by the conclusions of the Cochrane review in 2009, which suggested that supplementation led to a consistent mean weight gain of 2.3%, but failed to reduce length of hospital stay and offered no benefit to functional outcomes or improvements in quality of life.[20]

There have been concerns raised regarding the appropriateness and safety of PEG insertion for frail older people, particularly in the context of acute hospital admission. The 2004 report of the National Confidential Enquiry into Patient Outcome and Death (NCEPOD)[21] investigated PEG insertion, of which 95% were planned procedures, with 82% of patients aged over 70 years. Analysis showed that 43% died within 1 week and a further 63% had a definite risk of death within 30 days. In 19% of cases advisers considered the procedure to be futile.[21] The report recommended that:

> *there is a need for more comprehensive national guidelines for the use of PEG feeding, including issues of patient selection.*[21]

To date such guidance has not been forthcoming.

Re-feeding syndrome

The risks and consequences of supplementary feeding in malnourished patients must be considered. Re-feeding syndrome is thought to be caused by a potentially fatal shift in fluid and electrolytes resulting from hormonal and metabolic changes caused by rapid enteral or parenteral feeding after a period of established malnutrition.[22] In 1996 a prospective cohort study involving patients in intensive care units showed an incidence of 34%. Its pathophysiology is currently not well understood but those at risk must be identified early.[23] These include:

- BMI of <16 kg/m^2
- unintentional weight loss >15% within the last 3–6 months
- little or no nutritional intake for >10 days
- low levels of potassium, phosphate or magnesium before feeding.

In the following sections we will review the clinical evidence surrounding assisted feeding and related interventions in selected conditions common to frail patients.

Stroke

Half of patients who have a non-fatal stroke will have dysphagia, up to half will recover within 2 weeks, some will die and others will go on to require long-term feeding.[24] Dysphagia creates the risk of malnourishment and as a result increases the risk of adverse outcomes. Optimal management of these patients remains unclear.[24] A Cochrane review published in 1999 concluded that there was no significant evidence for nutritional supplements reducing mortality.[25] Two trials concluded that drug therapy (nifedipine) and speech and language therapy assessment (SLT), for the management of dysphagia in an acute setting did not improve end-of-trial dysphagia rates.[25]

A further Cochrane review in 2012 concluded that there was insufficient efficacy data for clinically assisted feeding on mortality and functional outcomes, but that starting feeding within 7 days of stroke onset may increase survival. It suggested that there was no clear advantage of PEG over NG feeding in the short term; however, if long-term nutrition is required (beyond 6 months), PEG feeding results in fewer treatment failures. Nutritional supplementation was associated with a reduction in pressure sore formation after stroke.[24]

Hip fracture

At the time of a fracture older patients are often already malnourished and subsequent poor oral intake may worsen outcomes, such as length of hospital stay. A Cochrane review published in 2006 of nutritional supplementation for hip fracture aftercare in older people, involving 1,940 patients, concluded that there was weak evidence for the effectiveness of protein- and calorie-rich oral feed supplements but no evidence of improved mortality by using NG feeding perioperatively.[26] Similar to acute stroke, improving nutrition postoperatively may reduce the risk of pressure sores.[27]

Pressure sores

Pressure ulcers affect 10% of people in hospitals and older people are at the highest risk. Several studies have suggested that poor nutrition is associated with the development of pressure ulcers. A Cochrane review in 2003 evaluated the effectiveness of nutritional interventions in preventing and treating pressure ulcers. In contrast to work undertaken in relation to stroke and hip fracture, this review was unable to establish any benefits of enteral or parenteral feeding.[28]

Clinically assisted feeding and dementia

Poor food intake is common in patients with dementia, often starting before formal diagnosis, and has a variety of causes: a failure to recognise food, loss of the normal physiological drivers of appetite due to changes in hypothalamic and limbic function, and at an advanced stage physical difficulty relating to neurogenic dysphagia.[29] It is at this stage that decisions around clinically assisted feeding are often made. In a US study involving 186,835 nursing home residents with advanced dementia, the prevalence of tube feeding was 34%.[30] This Cochrane review concluded that there was no evidence that enteral tube nutrition is effective in terms of prolonging survival, improving quality of

life, or leading to improved nutritional status or decreasing the risk of pressure sores.[30] It may actually increase the risk of developing pneumonia due to aspiration and increase mortality. The Royal College of Physicians supported this conclusion in their 2010 guidance.[31]

End-of-life care

At the end of life, a patient's desire for food may lessen. Good palliative care, rather than attempting to feed the patient, may become the more appropriate intervention. However, families and patients may have strong beliefs and opinions on clinically assisted feeding and hydration. Often their concern is that the lack of food or water is causing discomfort or pain. Some studies have concluded, however, that forgoing nutrition and hydration in the end-stages of life may improve patient comfort rather than being painful.[32] Water deprivation increases the production of endogenous opiates, inducing euphoria, and has been associated with a reduction in pain.[33]

A review of 70 prospective randomised controlled trials of nutritional support of cancer patients showed no clinical benefit to this patient population.[34] Often patients do not appear to experience hunger or thirst in the end stages of life and eating normal amounts can exacerbate nausea and abdominal discomfort.[35]

For those who are severely cognitively impaired, there is little evidence that thirst or hunger is significantly perceived. Patients often refuse the efforts by carers attempt to clinically feed.[36] A dry mouth is a poor clinical indicator of hydration state, may be equally associated with medication or mouth breathing, and should be managed through good nursing care.[37] Optimal mouth care is a key goal for any patient in receipt of palliative and in particular end-of-life care.

At the end of life it is important to consider the appropriateness of continuing artificial feeding and intravenous fluids, which may exacerbate pulmonary and peripheral oedema and increase secretions, which the semi-conscious patient is unable to manage.[38] Where withdrawal of hydration and nutrition is contemplated, the reasons for doing so must be clearly and carefully assessed, and decisions undertaken by the responsible clinician within the appropriate legal and professional guidance. When determining best interests, it is important to note that surrogate decision-making is particularly difficult for family members. A survey of surrogates regarding feeding in end-of-life care found that, at the time of the decision, 49% did not understand the risks of the interventions and 84% expected life prolongation, with only 48% being confident that the decision they made coincided with patient wishes.[39] A further study by Rosendal concluded that in up to one-third of cases the surrogates subsequently regretted their decision.[40]

Clinicians will generally articulate risks and benefits in terms of clinical evidence and outcomes. For patients and their families, perceived risks or benefits may be alternatively or additionally articulated in social or moral terms. Both perspectives have validity. The decision-making clinician must take this into account in leading discussions that determine anticipated overall benefit.

Professional guidance

The General Medical Council (GMC) has published professional guidance on end-of-life care.[41] It defines end of life as those likely to die within 12 months, ranging from imminent death (hours to days), those with advanced or progressive illness, to general frailty or patients with existing conditions that predispose to risk of dying from a sudden acute crisis. The GMC recognises that towards the end of life it is important to provide formal and effective palliative care that ensures the management of pain and distressing symptoms as well as providing support to the patients and their family. Palliative care should not only be considered for use in the last few days of life but also provided at any stage in the progression of a patient's illness.[41]

The GMC states:[41]

> *You must give patients who are approaching the end of their life the same quality of care as all other patients*

and that, when making decisions about potentially life-prolonging treatment, the decisions must not be motivated by a desire to end life, and thus a presumption in favour of prolonging life should be made. By making this presumption it will normally require that all reasonable steps to prolong a patient's life are made.[41]

The right to life does not include a right to life-sustaining treatment in all circumstances – there is no absolute obligation to continue to provide treatment if it would be futile. GMC guidance highlights that, where a doctor considers a treatment not clinically appropriate, they are not obliged to provide it.[41] Notwithstanding, rights must be taken into account in decisions about whether to provide an older person with life-sustaining treatment. Failing to provide life-sustaining treatment solely because of age may breach a number of fundamental human rights.[42]

If a patient is unable to achieve adequate oral nutrition or hydration then it necessary to consider clinically assisted nutrition: intravenous food or fluids, NG, PEG or RIG tubes. This is distinct from providing basic care such as assisted oral feeding. Although clinically assisted measures may provide symptom relief, or prolong or improve the quality of the patient's life, they are not without risk. In making decisions about these interventions with a patient or in their best interests, it is important to determine the overall anticipated benefit, weighing this carefully against the anticipated or known burdens to ensure that benefits outweigh burdens and continue to do so throughout the duration of treatment.[41]

There are many ethical frameworks for decision-making relevant to the provision of clinically assisted nutrition and hydration. Of overriding importance for clinicians are the guiding principles of preserving life and wellbeing where possible, and respecting patient choice where this can be expressed. The responsible clinician therefore has a duty to ensure not only the maintenance of a

balance in favour of overall benefit, but also the facilitation of ongoing effective communication with a patient (or his or her legitimate representatives) focused on choice.

Conclusion and key points

With an expanding older frail population, clinicians will be faced increasingly with decisions with regards to clinically assisted feeding for older people and at the end of life. Older patients are at increased risk of malnutrition, resulting in higher mortality and morbidity. It is important to address nutritional need early in order to prevent or mitigate these adverse outcomes.

The research evidence base for clinically assisted nutrition and hydration, either during acute illness or at the end of life, is largely unhelpful. In some circumstances interventions may lead to harm rather than benefit, for example as a result of re-feeding syndrome. Careful evaluation of the nutritional and underlying health status of an older patient presenting with acute illness remains an essential component of good medical practice. In addition there is a duty for clinicians to carefully determine overall benefit to an individual through a process of weighing burdens and benefits focused on explicit outcomes that may include recovery, symptom relief and/or prolongation of life. In doing so it is important to remember that family expectations and perceived benefits may differ greatly from the clinical outcomes articulated by the deciding clinician.

Responsible clinicians have a professional duty to be aware of, and understand, the clinical evidence base relating to decisions about clinically assisted nutrition and hydration. They also have a duty to elicit, understand and weigh the views of their patient, and where necessary their representatives. This is particularly important when available clinical evidence is limited. It is essential to use all available evidence, whether articulated in clinical, social or moral terms to determine overall benefit for a proposed intervention on an individual basis. This can only be undertaken through a process of facilitated patient choice utilising the available legal and professional decision-making frameworks. Any decision relating to clinically assisted nutrition and/or hydration in a frail older person who is considered to be nearing the end of their life must also include explicit consideration of the needs of that individual for formalised palliative care.

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