

United Kingdom guidelines for clinically assisted nutrition and hydration in the context of treatment and care at the end of life

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Abstract

Guidelines for care at the end of life can be useful resources not only for physician and healthcare workers, but also for patients and their families. The United Kingdom—a world leader in provision of end-of-life care—produces many such guidelines, which may be a contributing factor to its success in this area. One facet of end-of-life care that is of particular importance is the use of clinically assisted nutrition and hydration (CANH). Guidance around CANH gained attention in the United Kingdom around 2009, when the Liverpool Care Pathway, a protocol designed to help healthcare workers deliver evidenced-based end-of-life care, was criticized in the press and from some quarters of the medical community following complaints from patients' families regarding withholding or withdrawal of CANH. In this lecture we give an overview of this topic, ask what lessons we can learn from the Liverpool Care Pathway, introduce some of the current major clinical guidelines for CANH at the end of life, and give some focused discussion on the topic of Percutaneous Endoscopic Gastrostomy.

Introduction

Care at the end of life is of growing importance worldwide. With advancements in medical care making it possible for people to live longer lives, societies have an increasing responsibility to ensure that the final stages of those lives are as dignified as possible. However, care at the end of life is a multifaceted, difficult issue in which the wishes of the dying person, the wishes of grieving of the family, and the best intentions of medical care team can often be conflicting.

The 2015 Quality of Death Index ranked the United Kingdom (UK) as the best in the world for providing end-of-life care¹⁾. While advance care planning has done much to ensure the prioritization of the wishes of the dying person, detailed guidelines and policies are also in place to help the medical care provider navigate the difficult decisions that inevitably have to be made regarding treatment at the end of life. The National Health Service (NHS), the General Medical Council (GMC), and other organizations provide publications that are available online for physicians and care providers, and lay material for the general public. In a previous publication, which was an international review of guidelines for care at the end of life, we discovered that the UK had, at the time of publication many guidelines on this topic compared to other countries²⁾.

This lecture will focus upon one subject, namely the UK guidelines surrounding the provision of clinically assisted nutrition and hydration (CANH) in the context of providing good treatment and care for people reaching the end of their lives, with special attention to the policy surrounding Percutaneous Endoscopic Gastrostomy (PEG). Guidance around CANH gained major attention in the UK around 2009, when the Liverpool Care Pathway, a protocol designed to help healthcare workers deliver evidenced-based end-of-life care, was criticized in the press and from some quarters of the medical community following complaints from patients'

families regarding withholding or withdrawal of CANH. Since then, guidelines have continued to be produced, evolved, fine-tuned to meet the demands of healthcare providers across the country. The purpose of this lecture, therefore, is to ask what lessons we can learn from the now phased-out Liverpool Care Pathway, introduce some of the current major clinical guidelines for CANH at the end of life, and discuss in detail the problems with PEG. By reflecting on successes and failures of guidance on this topic it can help shape future guidelines and broaden our understanding of the issues at hand.

Food and drink versus clinically assisted nutrition and hydration

Caring for someone at a very fundamental level involves feeding their hunger and quenching their thirst. Feeding is a very important act. It is almost ritualistic and symbolic of care. As human beings we experience care through provision of food and drink throughout our lives, but it is particularly significant at birth and at the end of our lives, when we are unable to feed and care for ourselves. The fundamental nature of provision of food and drink is reflected in the guidelines from the GMC who state: "The offer of food and drink by mouth is part of basic care and must always be offered to patients who are able to swallow without serious risk of choking or aspirating food or drink"³⁾.

For patients who are not able to swallow without serious risk, provision of ANH, through some form of feeding tube, is considered as a means of providing nourishment. The GMC acknowledge that "some people see nutrition and hydration, whether taken orally or by tube or drip, as part of basic nurture for the patient that should almost always be provided"³⁾. British law, however, creates a clear distinction between these two forms of feeding: "Nutrition and hydration provided by tube or drip are regarded in law as medical treatment, and should be treated in the same way as other medical interventions"³⁾. As

such, like other medical interventions, treatment should be provided when and where it is appropriate for the patient, even CANH.

There is, however, an obvious tension here: something that is regarded as basic care (the provision of nourishment orally with food and drink) has shifted to medical intervention (the provision of nourishment artificially through feeding tube or drip). This distinction, while being very easy to unemotionally pen into law, is not easy for those who find themselves in a situation where they must make decisions on the behalf of others particularly at the end of life, when it is arguably impossible, and indeed undesirable, to remain emotionally detached. Artificial nutrition and hydration, however, can carry considerable risks, particularly for older adults. There are ethical and legal questions that must be addressed and thought through, to that end various organizations have published guidelines to aid healthcare professionals to provide appropriate care for patients at the end of their lives.

Lessons from the Liverpool Care Pathway

The Liverpool Care Pathway for the Dying Patient (LCP), a paper-based, evidence-based protocol, was created in the late 1990s to try to bring high quality end-of-life care to those dying in hospitals. The LCP aimed to provide “guidelines for best practice, focusing on symptom control, appropriate discontinuation of active treatments, psychological, social, and spiritual care of patients and their families, and frequent patient reassessment”⁴⁾. However, from about 2009, the LCP began to receive heavy criticism initially from within the medical community and later from the press⁵⁾. News headlines described the care pathway as a “pathway to death”⁶⁾. The term “Care Pathway” was itself problematic. Pathway in English is a singular word, implying that there is only one pathway – ultimately a pathway to death rather than a pathway to recovery. This problem might have been less pronounced had the creators of the

LCP given it a different name, or at least used the plural form ‘pathways’ rather than the singular ‘pathway’. In Western thought, there is strong emphasis on a person as an individual; thus, the idea that there would be a single pathway for end-of-life care does not suit the Western concept of self. In the context of a strong emphasis on patient choice, which is the prevailing idea in the British health care system, the LCP needed to reflect a greater sense of individualized care.

Perhaps the most controversial part of the LCP, especially regarding the public perception of it, involved the advice on appropriate discontinuation of active treatments, especially as this included the discontinuation of CANH. Some examples of news headlines surrounding the LCP controversy demonstrate this very clearly:

“It was murder, says son of woman ‘starved to death’ on Liverpool Care Pathway as he calls for police inquiry”⁷⁾

“‘They were treated like dogs waiting to be put down’: Son of couple put on ‘death pathway’ blasts decision to withdraw treatment”⁸⁾

“Pensioner placed on Liverpool Care Pathway WITHOUT family’s permission dies after spending eight days without food or water”⁹⁾

It is, however, within British law to withhold or withdraw clinically assisted nutrition or hydration if it is the patient’s best interests to do so. The 2010 GMC guidelines state: “If you judge that the provision of clinically assisted nutrition or hydration would not be of overall benefit to the patient, you may conclude that the treatment should not be started at that time or should be withdrawn”³⁾. The LCP advice surrounding this issue was not revolutionary; the problem lay perhaps more with the busy hospital context in which it was applied. The hospice or palliative care environment provides opportunity for counseling and dialog between patients, family members, and caregivers to discuss what is in the patient’s best interests and explain the reasoning for withholding or withdrawing treatment, and

gives them more time to come to terms with the situation. In the rush of a busy NHS hospital, doctors and nurses simply do not often have the time and resources to offer that vital part of end-of-life care.

NICE Guidelines

Since 2013, the LCP has gradually been phased-out of use in hospitals, and new guidelines, *Care of dying adults in the last days of life*, created by the National Institute for Health and Care Excellence, have since taken its place, known as the “NICE Guidelines”¹⁰⁾. These NICE Guidelines have a stronger emphasis on personalized care (part of section 1.3 deals with this subject directly), and section 1.4 is devoted entirely to the issue of maintaining hydration¹⁰⁾. *Care of dying adults in the last days of life* unfortunately does not address the subject of maintaining nutrition. The booklet is a 26-page document and, therefore, does not address any subject with the kind of detail that physicians and care providers need. They will perhaps best function as a basic reference guide.

GMC guidelines

In the section regarding the challenge maintaining hydration¹⁰⁾, the NICE Guidelines actually direct healthcare professionals to a section of the 2010 publication from the GMC *Treatment and care towards the end of life: good practice in decision making guidance* that deals with clinically assisted nutrition and hydration³⁾. At 92 pages, this publication provides far more detail on the various issues surrounding end-of-life care and also gives practical advice to physicians regarding the decision making process, including decision making models. The GMC guidelines provide eight pages of such advice for the subject of nutrition and hydration. They provide clear definitions of the issues including explanations of patients’ rights and British law and discuss some of the risks associated with CANH.

The Royal College of Physicians guidelines

Regarding the specific issue of oral feeding and CANH, the Royal College of Physicians together with the British Society of Gastroenterology published a working party report *called Oral feeding difficulties and dilemmas: a guide to practical care particularly at the end of life*¹¹⁾. This 100-page document is a detailed and thorough reference work for physicians that gives background information and advice on meeting the nutritional needs of patients at every stage of their capacity. The publication includes an assessment of the benefits and risks of CANH, and deals comprehensively with the ethical and legal issues involved. Of interest to the physician is the inclusion of case studies and, like the GMC guidelines³⁾, advice on working with patients to make difficult decisions.

British Medical Association guidelines

In 2018, the British Medical Association (BMA) in conjunction with the Royal College of Physicians, produced a guideline specifically on the use of CANH for people who lack capacity to make their own decisions, *Clinically-assisted nutrition and hydration (CANH) and adults who lack the capacity to consent: Guidance for decision-making in England and Wales*¹²⁾. This lengthy guideline comprehensively navigates this ethically difficult subject in a clear, accessible manner. The guideline covers the withdrawal and withholding of CANH, second opinions, best interests assessments, conscientious objections, etc. In Appendix 4, the BMA guideline includes detailed information about the legal background behind decision-making regarding CANH, including synopses of the landmark court decisions and legislation. Appendix 1 gives detailed practical guidance for “best interests decision-making” and Appendix 2 is a checklist to help physicians record evidence of best interests decision-making as it pertains to CANH. Having such guidance and checklist would provide clarity and assurance for the treatment team in difficult

decision-making situations.

The PEG problem

Across the NHS, procedure-specific guidelines for clinicians and lay materials for patients are published online and regularly updated. Of pertinence to this report are the publications related to CANH and among the various types of treatment, perhaps Percutaneous Endoscopic Gastrostomy (PEG) is the most controversial. The GMC guidelines do mention some of the risk associated with CANH in general³⁾, but the Royal College of Physicians guidelines give extensive details of the various risks associated with PEG for patients at the end of their lives¹¹⁾. They state that: “PEG placement in acutely ill patients with dementia could contribute to mortality”¹¹⁾ and that they “may cause more suffering than they relieve”¹¹⁾. A retrospective study of 719 patients in the UK who had died within 30 days of receiving a PEG found that 43% of the patients actually died within 1 week of receiving PEG; 82% were over 70 years old; and 97% of the patients had coexisting neurologic disease such as stroke, dementia, or Parkinson’s disease¹³⁾. The placement of a PEG, particularly in an older adult patient with a coexisting neurologic disease is not a decision that should be made without proper consideration. This information is, however, barely mentioned in some NHS guidelines for PEG. For example, in a pamphlet for patients from the North Bristol NHS Trust, *Percutaneous Endoscopic Gastrostomy (PEG) Radiologically Inserted Gastrostomy (RIG)*¹⁴⁾ and a pamphlet published by The Royal Marsden NHS Foundation Trust, *Having a gastroscopy and Percutaneous Endoscopic Gastrostomy (PEG) feeding tube*¹⁵⁾, while listing some of the possible complications of PEG, make no specific mention of the risks for older adult patients. This lack of information provided to the general public, especially around ethically and emotionally charged subjects like the provision of CANH complicates the decision-making process

and arguably contributes to misunderstandings between healthcare professionals and the public.

Conclusion

Johnston et al suggest that “all patients in whom PEG feeding is proposed should ideally be reviewed by a multidisciplinary team”¹³⁾. Likewise, many of the guidelines on the wider issue of end-of-life care stress the importance of the multidisciplinary team. This should help to ensure that from a medical point of view the right decision is being made; there is after all “safety in numbers”. Care at the end of life is complicated and decisions are difficult, but care and decision-making should not be the sole responsibilities of doctors, patients, or family members, but rather the collective wisdom of all interested parties. In the interests of respecting patients’ choice at the end of life, guidelines and information distributed to the public need to help facilitate informed and educated decision-making. The failure of the LCP taught us that guidelines need to be focused on personalized care – there is not a “one-size-fits-all” care pathway, we all need to walk our own pathway in life and in death. That does not mean, however, that we have to walk that path alone.

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