To Hydrate or Not at the End of Life

Abstract:

Most patients at the end of life gradually stop eating and drinking. Family members and carers often experience high levels of emotional distress when this happens, fearing that not providing food or fluid by some artificial means will hasten death or cause discomfort. Whereas retrospective studies on artificial nutrition in advanced illness have shown a consistent lack of benefit, the question of artificial hydration is more controversial and has received increased attention in recent years. Some of the ethical debate centres on whether providing fluids by an artificial route constitutes basic care, to which the patient would be automatically entitled, or a medical intervention, which according to the circumstances may or may not be justified. Whether providing fluids by an artificial route constitutes basic care, to which the patient would be automatically entitled, or a medical intervention, which according to the circumstances may or may not be justified, includes: who should decide? and by what process? A very practical dilemma, however, often precedes these questions. This dilemma of diagnosing the dying phase of an illness, has been described how the trajectories of illnesses vary considerably between cancer, organ failure and dementia. The dying phase in cancer is easier to characterise than the other two but even here there is some uncertainty and this can make the decision process harder.

There have been arguments on both clinical and ethical grounds, for and against providing parenteral fluids in dying patients. In spite of this debate there has been little clinical research focusing on artificial hydration at the end of life. Partly this is due to the difficulties of conducting research in this (extremely vulnerable) population. These difficulties are both ethical (is it right to randomise dying patients to a treatment or placebo, either of which could harm them? How can a dying person consent to such a trial?) and operational (eligibility of patients onto a trial, establishing informed consent, measuring benefit or harm of an intervention, lack of a follow-up period).

A Cochrane Review was published in 2008 on medically assisted hydration for adult palliative care patients. The objective was to determine the effect of artificial hydration on both quality of life and length of life. From a literature search only five relevant studies were identified, all of variable quality and power, and a quantitative analysis was not possible. Two were randomised control trials and three were prospective control trials. Overall the results were mixed: one trial found that the specific symptoms of myoclonus (a symptom of opioid toxicity) and sedation were improved with artificial hydration, one trial found that symptoms associated with intestinal drainage and chest secretions were worsened with fluids, three were inconclusive. The authors concluded that there were insufficient good quality studies to allow strong recommendations to be made. In Ireland the Irish Association for Palliative Care (IAPC) published a Position Paper on Artificial Hydration in Terminal Illnesses last year8. Here artificial hydration is considered to be a medical intervention and not part of normal comfort care. Its withdrawal or non-commencement may therefore be justified if it is excessively burdensome or futile.

Two common clinical scenarios are considered. The first is where a competent patient requests not to be given artificial hydration or, if lacking capacity, has previously authorised an Advance Care Directive in which he/she requested not to have AH should certain circumstances arise. Withholding fluids in these situations is clearly justified. The second scenario is where the patient has not declared her wishes in an Advanced Care Directive but is now dying. The position of the IAPC is that AH is only appropriate in situations where a clinical deterioration is potentially reversible (e.g. vomiting, diarrhoea, excessive diuretics, hypercalcaemia) and not due to progression of the underlying illness. It is unlikely to confer significant benefit in patients who do not have a reversible cause for their deterioration. In reality there may be some uncertainty as to how much is reversible or not. Policies of always or never using AH are ethically indefensible and decision-making is a process based on the circumstances unique to the patient rather than an abstract principle.

The IAPC stresses the importance of good communication with the family on the potential benefits and burdens of artificial hydration, and reassurances that the patients comfort is of paramount importance. A decision should only be made following consultation with the multidisciplinary team and the family, aiming for a consensus. In some situations a short trial (e.g. 48 hours) of artificial hydration may be tried, providing this does not subordinate the best interests of the patient to relieve the concerns of the family. In more difficult cases it may be useful to discuss with a local clinical ethics committee. In the UK, the National Council for Palliative Care (NCPC) published guidelines in 2007 on artificial nutrition and hydration (ANH) in end of life care for adults applied the legal framework contained in the Medical Capacity Act (UK, 2005) to the decision-making process. Although legal terms differ slightly, the position of the NCPC is largely identical to that of the IAPC and these guidelines should also prove applicable in the Irish context. The Law Reform Commission of Ireland published a report on advance care directives in 2009 in which it distinguished between basic care and life-sustaining treatment that where there is no possibility of recovery or where the administration of ANH would be considered invasive and providing no real comfort to the patient, it would be considered life-sustaining treatment. For the patient who is clearly dying, artificial hydration qualifies as life-sustaining treatment rather than basic care.

In conclusion, it is unlikely that further research will provide easy answers to the question of parenteral fluids at the end of life in a one size fits all manner. The decision to give or withhold fluids should be informed not only by a background knowledge of ethical principles, state legislation and scientific evidence but also by careful consideration of the circumstances of the individual patient and open discussion with families to reach, if possible, a consensus.

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References