

Current concepts in medicine

Dehydration in the terminally ill – iatrogenic insult or natural process?

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Summary

The question of whether terminally ill patients should artificially be given fluids has been debated since before palliative care became a recognised specialty. Arguments have been adduced from physiological, comfort, legal psychological, and emotional perspectives. Palliative care specialists agree that the priority is preventing the symptoms associated with dehydration, rather than the dehydration itself. However, the majority of terminally ill patients are cared for in settings outside hospices, and those admitted to hospital will tend to be exposed to a more technical approach. There are no randomised controlled trials in this area, and although an ethical minefield, we should not be afraid to manage individual patients according to the principles of palliative care where control of symptoms, not normalising of physiological variables, is the primary objective.

Keywords: dehydration, terminal illness

There is a continuing debate about the role of artificially providing fluids, whether by the enteral or parenteral route, in the terminally ill patient. In such a patient the goals are different from those in a patient undergoing curative treatment. In the former, the goal is palliative care. The definition of 'palliative care' is "the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families".¹ Given that "quality of life is a construct whose conceptual definition currently lacks full consensus",² it is hardly surprising that an issue relating to such a debated principle should be contentious and be the subject of continuing discussion. Many studies have examined the physiological, psychological, legal and ethical aspects of the role of artificial hydration in palliative care. This paper is an attempt to review the more important publications relating to this complex subject.

Changing attitudes

An investigation undertaken in 1983 into the attitudes of doctors towards the hydration of a hypothetical comatose dying patient with widespread malignant metastases showed that 73% of medical staff would artificially rehydrate the patient.³ Attitudes, however, appear to be changing. A survey in 1989, using a similar hypothetical example, found that now 53% would artificially hydrate,⁴ while a further study in 1992 found that only 44% would do so.⁵ These results show an obvious change in clinical management, although 44% remains a large proportion.

Electrolyte imbalance

In the 1989 study, where hydration therapies were utilised, the overwhelming reason cited was to prevent the potentially unpleasant side-effects of dehydration and its resulting electrolyte imbalance.⁴ This was mirrored in another 1992 study showing that many nurses working in general hospitals generally believed dehydration caused a wide range of unpleasant symptoms.⁶ Specific side-effects quoted include apathy, depression, dysphagia and oesophageal dysfunction⁷; dysuria and increased risk of urinary tract infection⁸; headaches, nausea and vomiting⁹, and postural hypotension and decreased skin perfusion.¹⁰

Conversely, others have argued that dehydration can itself confer benefits, such as reducing the need for oropharyngeal suction,¹¹ and that hydration can cause a full bladder leading to incontinence and distress¹². Further, in cases of extreme malnutrition and dehydration there may be analgesic benefits.¹³ It has also been claimed that the infusion itself creates a barrier and makes "a cuddle almost impossible".¹²

With these two sets of opposing views, the issue is often side-tracked at this point as clinicians argue over an apparently scientific issue. However, studies in 1984¹⁴ and 1991¹⁵ largely discredited the theories that electrolyte imbalance is essentially affected by the use of artificial hydration therapies or that non-hydrated patients have vastly altered electrolyte balances. This is further underlined by one author's opinion that doctors "may be reassured by the use of electrolytes and such action might impress the relatives that something is being done. But rehydration does no good. It is normal, and more comfortable, to die slightly dehydrated".¹²

Patient comfort

"The traditional goals of medicine are to cure, sometimes, to relieve, occasionally, and to comfort, always."¹⁶ Therefore, it is important to ask

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oneself what difference it makes to the patient what their electrolyte balance is, if they are receiving appropriate care to maintain comfort. Observations based on a study of four geriatric wards in Sweden led to claims that when the patient is unable to take adequate amounts of food and drink, if the condition is accepted, the patient dries up, becomes somnolent and dies peacefully within a week or so apparently without thirst, hunger or pain.¹⁷ This statement may, however, give the impression that it is necessary to do nothing whatsoever to ensure the patient's comfort.

This contrasts sharply with a Canadian study conducted in 1993 in which the severity of symptoms such as thirst, dry mouth, nausea, variations in fluid intake and concentrations of sodium and urea, were studied in 52 patients receiving palliative care. It was concluded that, whilst feelings of thirst and dry mouth scored highest (60.0 mm and 53.8 mm, respectively, on visual analogue scales), there was no demonstrable difference between severity and fluid intake.¹⁸ This clearly highlights the need for effective nursing care in the terminal phase to maintain patient comfort. It also reflects the view that clinical audit is the preferred method of ensuring 'best practice'.¹⁹

Fear of litigation

It has also been proposed that doctors continue intravenous infusions to protect patients from diagnostic error and to avoid charges of cost-cutting in an ever-increasing climate of cost-effective care.¹⁶ This would perhaps explain the finding that only 68% of clinicians in favour of artificial hydration would institute it at a rate sufficient to maintain hydration.⁴ It is possible that doctors feel under pressure in an increasingly litigious society to prevent charges of negligence by being seen to 'do something', thus allowing them to claim on the eventual death of the patient, that everything possible was done.

A similar attitude was noted in the US, where physicians and nurses were reluctant to withdraw artificial hydration therapies as a result of fear of legal repercussions.¹¹ However, in cases where physicians have been indicted for murder following withdrawal of treatment from dying patients, the American courts have ruled that death was due to the primary disease process rather than the discontinuation of medical treatments.^{13, 20}

Lack of acceptance

Maintenance of hydration, whilst understandable, goes against the belief that "denying the biological reality of approaching death renders the patient-care worker relationship paradoxical, inducing anxiety in both patient and care worker, and jeopardising the quality of emotional contact".¹⁷ Advances in medicine have been able to push forward the boundaries of what is treatable in so many aspects of care, while a change in attitude has occurred towards death, resulting in the current commonly held belief that home is not the most adequate place to die.²¹ This, it is felt, has led to loss of acceptance of the biological reality and caused people to be unable to come to terms with their own mortality.²²

From hospice to hospital

Whilst many authors experienced in hospice care would support the view that dehydration may well be beneficial to the dying patient,²³ the need for care to relieve satisfactorily the most common symptom of dehydration, namely a dry mouth, must not be forgotten. (For this, 1–2 ml of water delivered by pipette into the dependent side of the mouth every 30–60 minutes has been proposed; alternatively, small ice chips may be utilised.²³) Moreover, if relatives can be involved in this care, given support and education, then an exchange of roles can be made.²⁴ In caring for 'their' patient, relatives can feel more responsible for them and avoid the situation in which the patient becomes the property of staff, causing relatives to feel helpless.²⁰

However, the fact remains that only a relatively small proportion of dying patients are cared for in hospices. A survey conducted in 1994 in the Exeter Health District found that in a one-year period only around 10% of the 1022 deaths attributable to cancer received their terminal care in a hospice.²⁵ Whilst it is accepted that there may well be some geographical variation in these figures, there would appear to be an increasing number of patients admitted to hospitals for their terminal care. For example, in 1965 the Registrar General's statistics for England and Wales showed that 62% of deaths occurred outside of the patient's home, while by 1975 this figure had increased to almost 70%.²⁶ A

Spanish study conducted in 1993 found that 90% of all deaths occurred in hospital.²¹

This move into hospital care renders the patient more likely to receive artificial hydration therapy in the terminal phase than if they remained at home or were nursed in a hospice. Indeed the statement that “technological intervention in death is the antithesis of the hospice approach” underlines this.¹² However, these interventions may also reflect the difference in function and public acceptance between hospital care, which is supposed to be curative, and hospice care, which clearly is not. Also it is felt it is much harder to refrain than to act in the face of death.³

Emotive issues

Fluids are vital to the life cycle and may be seen as a ‘symbol of life’. Furthermore, there is a strong link between provision of food and fluids and care giving.²⁷ This is supported by the suggestion that the desire to offer food and water is a powerful natural instinct,²⁸ and by the statement “the simple act of offering to allay hunger and to slake the thirst of a dying patient is deemed across time and cultures to be not only right but good. Denying food and water to anyone for any reason seems the antithesis of expressing care and compassion”.²⁷

Since dehydration may also hasten death,¹³ carers and staff may have to deal with not only the emotive issues of appearing to deny water, but also of accepting that death is near, or nearer, as a result. Relatives of the dying patient may require considerable time spent explaining the reasons for the non-institution of artificial hydration therapy, as often it is seen as synonymous with providing nutrition.²⁹

Ethical considerations

The issue of whether or not to institute artificial hydration therapy in the terminally ill patient is an ethical minefield, and the biggest practical problem may be finding out the patient’s wishes and feelings.²⁰ A Japanese study conducted in 1993 regarding patients’ wishes in terminal care showed that 80% of patients preferred candid information about diagnosis and prognosis, and 66% of patients preferred pain control over measures to prolong life.³⁰ It is acknowledged, however, that the ‘mind set’ of the Japanese may well be different to that of their British or European counterpart, and these findings may reflect this.

The guidelines established by the US President’s Commission for the study of Ethical Problems in Medicine and Biomedical and Behavioural Research in 1983 found that discontinuing medical hydration to be ethically acceptable when, from the patient’s point of view, it is more “burdensome than beneficial”.³¹ In addition, the British Medical Association Working Party on Euthanasia believed that “tubes for nutrition and hydration . . . are warranted only when they make possible a decent life”. However, they stressed “the team . . . must discuss with relatives whether this form of treatment is thought to be justified”.³²

The intake of food and fluids is universally recognised as an everyday activity necessary to sustain life. When a person becomes unable to take in his or her own food and fluids the law does not distinguish between artificial feeding and the provision of, for example, antibiotic therapy.³³ However, the judgement in the case of Tony Bland by the High Court in 1992 held that artificial nutrition and hydration are, like artificial ventilation, medical treatments, in which case doctors may take a clinical decision to discontinue them.³⁴ When the case was taken in appeal to the House of Lords in 1993, their Lordships’ judgement supported the original findings but ruled as unlawful any artificial intervention to hasten death as a positive act of ‘commission’ (as opposed to an ‘omission to struggle’).³³ Lord Goff pointed out that sanctity of life was not absolute,³³ and, ultimately, as stated in 1988, “while saving life is a legitimate goal, prolonging death is not”.³⁵

Palliation

Concerns about hydration of terminally ill patients occur in a variety of circumstances and for a variety of reasons. The issues involved represent a complex interplay of physical, psychological, emotional, and social factors. Once artificial administration of fluids has commenced, it can be very difficult to make a decision to discontinue such treatment. In contrast, if enteral or parenteral administration routes have not already been established, the issue of whether to ‘inflict’ such treatment on the patient may not arise.

It is important to differentiate between the common symptom of thirst and the physiological state of dehydration. The former is by no means always a result of the latter, and palliation of thirst, even when the result of dehydration, is not always best managed by the administration of fluids. Simple but assiduous mouth care usually suffices. It is of paramount importance to be aware of whose distress one is trying to palliate – is it the distress of the patient, the patient's relatives, or the caring staff? Often insight into these factors becomes lost as the patient deteriorates. It is vital to keep questioning “who am I really trying to help?” Until the owner of the problem has been explicitly identified, the most appropriate solution cannot be decided, let alone implemented.

Conclusions

Before a decision is made as to whether or not to hydrate artificially, it is clear that the diagnosis that the patient is indeed, terminally ill must be accurate. Once this is confirmed and the decision to commence palliative care rather than active treatment is taken, a crucial question to be considered is the benefit of an infusion to the patient. The studies conducted in 1984 and 1991 tend to negate the arguments proposed for maintaining electrolyte balance and the fear of litigation discussed cannot justify an inappropriate treatment. However, there is clearly a need to offer effective mouthcare to relieve feelings of thirst and a dry mouth, regardless of whether or not the patient is hydrated.

The feeling that modern society has lost its ability to accept death as a biological reality is not helped by the lack of candid acknowledgment expressed by medical and nursing staff, and does not appear to accord with patient wishes. The need to involve relatives in the discussion and decision process is stressed by the British Medical Association's findings and may help to avoid hydration being seen as synonymous with nutrition. Additionally, involvement of the relatives in the care of 'their' patient may help to avoid feelings of helplessness.

The move into caring for terminally ill patients increasingly in a hospital setting, with such conflicting needs from the acutely ill, requires clinicians of all disciplines to re-evaluate their management and perhaps to adopt a more holistic approach to palliative care. Emotional support of the relatives of a dying patient has long been an accepted nursing role requiring skill and compassion. That this is, at times, compromised by the conflicting deteriorating condition of the patient on the one hand, and ongoing medical treatment on the other, cannot be doubted. Therefore, whilst the decision whether or not to institute artificial hydration therapy in the terminally ill patient is clearly a complex one, making it impossible to provide a rule applicable in all circumstances, if one is aware of the factors involved in any specific case and the findings of relevant research, it is more likely that a considered and appropriate decision may be reached. Our experience is that it is rarely necessary artificially to provide fluids to terminally ill patients whilst maintaining full palliative care; symptom control can be quite effectively achieved in less invasive ways. However, occasions arise when a patient requests it, or empirically feels the better for it. Being able to find out what suits the individual patient best is the key to this question. Furthermore, where this decision is taken in conjunction with the relatives, the quality of emotional contact possible between patient, carer and relative will be greatly enhanced.

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