On withholding artificial hydration and nutrition from terminally ill sedated patients. The debate continues

Gillian M Craig  retired Consultant Geriatrician, Northampton

Abstract
The author reviews and continues the debate initiated by her recent paper in this journal. The paper was critical of certain aspects of palliative medicine, and caused Ashby and Stoffell to modify the framework they proposed in 1991. It now takes account of the need for artificial hydration to satisfy thirst, or other symptoms due to lack of fluid intake in the terminally ill. There is also a more positive attitude to the emotional needs and ethical views of the patient's family and care-givers. However, clinical concerns about the general reluctance to use artificial hydration in terminal care remain, and doubts persist about the ethical and legal arguments used by some palliative medicine specialists and others, to justify their approach. Published contributions to the debate to date, in professional journals, are reviewed. Key statements relating to the care of sedated terminally ill patients are discussed, and where necessary criticised.

Introduction
I welcome the discussion that has been generated by my paper in this journal, on the subject of withholding nutrition and hydration in the terminally ill. I criticised a framework for palliative care advocated by Ashby and Stoffell. My central theme was the issue of the need for artificial hydration when a patient is rendered incapable of swallowing by sedation. I argued that to withhold hydration is dangerous medically, ethically and legally, and can be disturbing for relatives.

At the time of writing I am aware of six papers and two letters that have been published in reply to this journal and two papers elsewhere. Gillon touched on legal aspects and raised the question of the need for formal mediation procedures. Wilkes, in a gentle and broadly-based commentary, shared some of my anxieties. Ashby and Stoffell continued the debate in a wide-ranging response and others focused on clinical aspects. The issues raised have been considered by the ethics committee of the Association for Palliative Medicine in the United Kingdom, by the board of the Cancer Relief Macmillan Fund, and by senior people in many walks of life. This paper summarises and extends the debate as it has developed in professional journals.

The subject under discussion straddles the boundaries of medicine, ethics and law, and strays into other academic areas too. The debate could easily get out of hand. In replying to papers that have appeared to date, I will not engage in detailed discussion of concepts such as care, needs, proportionality of medical interventions and processes of communication, although the discussion that follows touches on these issues in several places. To shift the focus of the argument into these areas, as proposed by Ashby and Stoffell, could be detrimental to progress. There are matters arising which need to be clarified before the agenda moves on. It is important to continue the debate on a level that will be of practical assistance to medical practitioners and possibly lawyers, who may be embroiled in the management of these difficult cases.

Clinical aspects

NEED FOR ARTIFICIAL HYDRATION IN SOME CIRCUMSTANCES IS ACKNOWLEDGED
I am glad to say that Ashby and Stoffell have amended their framework for palliative care to take account of some of my criticisms. They now say, with some preamble, that "artificial hydration may be required in the terminal phase to satisfy thirst, or other symptoms due to lack of fluid intake", and admit that "the emotional needs and ethical views of the patient's family and care-givers must be acknowledged and considered". They add that "if artificial hydration and nutrition are identified as necessary for comfort by attending staff or family members, and may be effective in achieving the stated aims, then they should not be refused".

Dunlop et al agree that there are rare occasions when it is justifiable to give subcutaneous fluids for the sake of the family, but do not recommend the routine use of intravenous or subcutaneous fluids. They distinguish between sedation used in terminal delirium, and sedation used in patients who are not

Key words
Hydration; nutrition; sedation; euthanasia; terminal care; law.
actually dying. They imply that in the latter situation problems with hydration rarely occur and so their discussion stops short of the ethical dilemma at issue."8

Dunphy et al in a brave and balanced discussion of the whole issue of rehydration in palliative or terminal care, stress the need to make "genuine and unprejudged assessments of the relevance of dehydration to each individual’s clinical presentation, and above all to be responsive to the wishes of the family.”10

RISKS OF ARTIFICIAL HYDRATION ARE EXAGGERATED
Ashby and Stoffell exaggerate the risks of artificial hydration quite considerably.7 Dunlop et al comment that no studies to their knowledge have demonstrated any adverse effects from fluid therapy, but advise caution if the serum albumin is low.8 Artificial hydration could be harmful in patients with cerebral oedema,5 cardiac failure, or any condition where symptoms are related to fluid overload. There will also be situations where fluid restriction is helpful, for example in patients with inappropriate secretion of anti-diuretic hormone – a condition that is found in some patients with cancer. All medical intervention must be used with clinical discretion. Some patients may benefit initially from a reduction in fluid intake, or cessation of artificial hydration and alimentation (AHA), but no one can survive indefinitely without sustenance.

RISK OF MISDIAGNOSIS AND UNDERTREATMENT
Ashby and Stoffell fail to understand the basis for my general concern. They take a comment about the need to buy time for assessment by energetic rehydration as a cue to launch into a tirade about technological brinkmanship. Yet they admit that when accepting patients for palliative care they have to “insist on fuller clinical information than some referring doctors think is really necessary for palliative care”. The inference to be drawn is that patients are being labelled as terminal on inadequate grounds – which, to coin a phrase used by Ashby and Stoffell, is my point entirely. The case reports I gave to illustrate this point were dismissed as “hard cases which can be mobilised to undermine any approach”. Actually they were hard cases that could represent the tip of an iceberg. Who knows how many patients die at home, or in hospital labelled as terminal, misdiagnosed and undertreated? As Wilkes observed, dehydration occurs far too frequently, far removed from the territory of palliative care.4

ARTIFICIAL NUTRITION
Dunlop et al rightly consider hydration and nutrition as separate issues.8 My main concerns relate to hydration, as the need for long term nutritional support with all its potential difficulties will rarely arise in terminal care. Although the administration of conventional dextrose solutions via a peripheral vein does not constitute full nutritional support,8 it does provide some useful calories in the short term, and is often given on medical and surgical wards for one or two weeks, to tide over patients who cannot eat. Dextrose solutions should not be given subcutaneously.

THE QUESTION OF THIRST
Ashby and Stoffell claim that I allege that sedation is used to mask the effects of dehydration or starvation.7 I did not say this, although it may well be so in some cases. On the question of thirst in general there is a hint of irritation and dismissal in their response to my comments, and they fail to appreciate that it is the relatives’ concern about suffering that I describe. It is no good brusquely referring people to the literature. Jo Blogs is not aware of the literature, all he sees is someone apparently dying of thirst or starving to death. That is the public perception of the situation, and in some cases they could be right. Moreover the literature is not uniformly reassuring on this point.

McCann and co-workers found thirst and/or a dry mouth to be a major symptom in 66% of 32 patients initially, with hunger being less of a problem, despite severe protein-calorie malnutrition.11 Thirst tended to decrease as death approached, despite probable dehydration. Anorexia may have been due to fasting, underlying disease or narcotic administration.11 Dunlop et al comment that most terminally ill cancer patients reach a point during their general decline when they first stop eating, and subsequently stop drinking.8 They make the interesting suggestion that the normal homeostatic mechanisms controlling fluid intake and fluid balance may be altered in the dying process. All the evidence in support of this suggestion needs to be carefully and impartially reviewed, but the letter by Waller to which they refer is open to criticism.6

Much remains to be discovered about the pathophysiological sequence of events, as some changes may prove to be reversible. Does severe dehydration, for example, suppress thirst in cancer patients, as it does in the healthy elderly? If so the result would be an escalating spiral of decline. Is it not time that someone studied the beneficial effects of rehydration in terminal care?

Clearly if patients have stopped drinking because of an irreversible decline it is one thing, but if they are suddenly rendered incapable of eating or drinking by sedation it is another. It is the latter situation that creates ethical problems.

THE NEED TO KEEP INTERVENTION SIMPLE
I am not advocating artificial hydration and nutrition in all dying patients irrespective of the circumstances, nor did I propose, as Ashby and Stoffell try to imply, “that provision of alimentation and hydration is a truly ordinary measure, with the means of delivery being irrelevant … even when a person is dying.”9 I
The legal question

Legal matters are covered in some detail by Ashley and Stoffell, as discussed by Professor M. W. D. M. and Stoffell, assisted by the Centre for Medicine, Ethics and Law, at the University of St. Andrews, in the wideranging discussion and scattered references from throughout their research papers, cited in the reference list at the end of the paper. In this section, we discuss the implications of the legal and ethical issues involved.

The legal issue is whether the provision of hydration or nutrition in terminal care is a treatment that is necessary and justifiable, or whether it is an act of futility that may result in discomfort or distress to the patient.

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the treatment. Thus it could avert the need for lengthy, costly and distressing inquiries after death.

2. CASE STUDIES IN ENGLISH, IRISH AND SCOTTISH LAW

There is still no case law on the issue of abatement of artificial hydration and alimentation in the dying, and the most relevant legal deliberations relate to the case of Airedale Trust v Bland in England,16 the Irish Supreme Court case in the Republic of Ireland,17 18 and the case of Mrs Johnstone of Lanarkshire, which has clarified the law regarding patients with a persistent vegetative state (PVS) in Scotland.19

The Bland case ruling applied strictly, and only, to the situation in that case16 20 and should not be extrapolated to other clinical situations.1 However, Ashby and Stoffell have done just that, saying “… if AHA was not required for Bland, who unlike the dying person was not actually or actively dying of a progressive fatal condition at the time of the judgment, there is even less basis for saying that it is required for all dying persons.”17 This is a very rash statement. Firstly no one is saying that AHA is required for all dying persons. Secondly some patients who require sedation in palliative care are not actually dying, nor are they necessarily unconscious. Thirdly the statement demonstrates an alarming lack of appreciation of the exceedingly careful ethical and legal deliberations that led to the decision in the Bland case. If society takes a decision about one patient with PVS so seriously, surely equally serious thought should be given to matters of hydration and nutrition in sedated patients with incurable disease. The shorter time scale in the dying does not eliminate the legal and ethical dilemmas. Fourthly the statement overlooks the major differences in mental state and underlying pathology between a terminally ill patient who is sedated, and a patient with PVS.

The Irish Supreme Court case

This concerned a 45-year-old woman in a near PVS, who retained some ability to recognise people, but could not move or communicate, following brain damage sustained in a minor operation 23 years earlier. The court ruled in May 1995 that she could be allowed to die by withdrawal of nourishment. The chief justice took the view that the true cause of the woman’s death would be the injuries she sustained in 1973, and not withdrawal of nourishment.17 Mr Justice Lynch said that what he had to decide was not the morality of the course that the family sought to follow, but the lawfulness of it.18

The Irish Medical Council, in a statement issued in August 1995,21 saw no need to alter its ethical guidelines, so leaving any doctor who assisted in withdrawing AHA open to disciplinary action. The council emphasised certain paragraphs which are of relevance to the present discussion.

- Doctors must do their best to preserve life and promote the health of the sick person.
- Medical care must not be used as a tool of the state to be granted or withheld or altered in character under political pressure.
- Where death is imminent, it is the doctor’s responsibility to take care that a patient dies with dignity and with as little suffering as possible. Euthanasia, which involves deliberately causing the death of a patient, is professional misconduct and is illegal in Ireland.

They also quoted articles two and four of Principles of Medical Ethics in Europe21:
- Article 2: In the course of his medical practice a doctor undertakes to give priority to the medical interests of the patient. The doctor may use his professional knowledge only to improve or maintain the health of those who place their trust in him; in no circumstances may he act to their detriment.
- Article 4: The doctor must not substitute his own definition of the quality of life for that of his patient.

Finally the Irish Medical Council added their view that “access to nutrition and hydration is one of the basic needs of human beings. This remains so even when, from time to time, this need can only be fulfilled by means of long-established methods such as naso-gastric and gastrostomy tube feeding.”21

The Scottish Court of Session case. Law Hospital Trust v Johnstone

The final judgment in the case of Mrs Janet Johnstone, who has had PVS for four years following a drug overdose, was given recently. According to reports in The Guardian,19 Lord Cameron of Lochbroom, after hearing evidence, passed the case on to the Inner House of the Court of Session for legal guidance. Five senior judges headed by Lord President Hope, declared that Lord Cameron would, if he chose, be entitled to grant requests that artificial feeding be abandoned. However, they warned that they had had no right to grant Mrs Johnstone’s doctors immunity from prosecution for murder. Scotland’s senior law officer, the Lord Advocate, Lord Mackay of Drumadoon later stated that he would not “authorise the prosecution of a qualified medical practitioner (or any person acting on the instructions of such a practitioner) who, acting in good faith and with the authority of the Court of Session, withdraws or otherwise causes to be discontinued life-sustaining treatment or other medical treatment from a patient in a persistent, or permanent vegetative state, with the result that the patient dies”. Permission to cease AHA was finally granted by Lord Cameron.19 Immunity from prosecution cannot automatically be extended to treatment-limiting decisions in the dying, or the disabled. Society is now, rather painfully, through the courts, deciding where the line should be drawn.

It cannot be said that there is universal agreement that AHA can be regarded as medical treatment that can be stopped if deemed to be futile. Grave doubts
remain, as evidenced by the Irish Medical Council’s statement, Lord Mustill’s unease concerning the Bland case, the views of the House of Lord’s Select Committee on Medical Ethics, and comments made by the Hon Mr Justice Ognall when discussing the hypothetical case of a patient whose severe pain could only be controlled by general anaesthesia. He drew attention to subtleties of distinction between switching off a life support system, as in the Bland case, and the withdrawal of nutrition and hydration in the latter situation. The House of Lords Select Committee were unable to reach a decision about whether nutrition and hydration, even when given by invasive methods, may ever be regarded as treatment, which in certain circumstances it may be inappropriate to initiate or continue.

3. THE PRINCIPLE OF DOUBLE EFFECT
The medical profession, supported by the legal profession, tend to shelter behind the principle of double effect. Ashby and Stoffell are no exception, arguing that “the influence on timing of death should be of secondary consideration to the comfort and dignity of the dying person.”

The principle of double effect was used by the judge in the case of R v Adams in 1957. It was alleged that Dr Adams had killed a patient affected by a stroke, by giving large doses of heroin and morphine. He was acquitted, the judge saying: “If the first purpose of medicine, the restoration of health can no longer be achieved, there is still much for the doctor to do, and he is entitled to do all that is proper and necessary to relieve pain and suffering, even if the measures he takes may incidentally shorten life.” Forty years on standards of medicine have changed. If all that is proper and necessary is done, there should rarely be any need for life to be shortened.

Anglican and Catholic Bishops have recently reaffirmed their support for the principle of double effect, noting that “There is a proper and fundamental ethical distinction ... between that which is intended and that which is foreseen but unintended.”

I have argued elsewhere that the principle of double effect is open to abuse, and could be quoted in the defence of medical practitioners whose standards of care and intentions are open to question. Where the side-effects of a treatment, such as sedation, are predictable, potentially lethal, and easily overcome by simple measures, failure to use such measures could be regarded as negligent. Some witnesses to the House of Lords Select Committee also expressed concern and suggested that the double effect of some therapeutic drugs, when given in large doses, was being used as a cloak for euthanasia. The committee, however, expressed confidence in the medical profession, and in the ability of a jury to evaluate a doctor’s intention. The profession must prove worthy of such public trust.

4. THE EUTHANASIA QUESTION
Notwithstanding the objections raised by Ashby and Stoffell who say “there is no place for emotive language about killing patients in this context,” a consideration of this matter is not out of place in this debate. I posed the questions: “Are you, by withholding fluid and nourishment, withholding the means of sustaining life? In short are you killing the patient?”

Gillon refers to moral distinctions between killing, and letting die. The Hon Mr Justice Ognall points out that “the distinction between deliberate acts intended to kill ... and letting die ... is not free from difficulties. Is a doctor who allows a terminally ill patient to die guilty of murder? Our law says no, but, providing his intention in omitting to act is to hasten the patient’s death, what is the distinction in that circumstance between an act on the one hand, and an omission on the other?”

The current legal position regarding euthanasia in Scotland, England and Wales involves two elements: “a) a guilty act and b) the necessary intent. In general an omission to prevent death is not a guilty act, and cannot give rise to a conviction for murder. But where the accused was under a duty to the deceased, for example as his parent, nurse or doctor, to carry out the act which he omitted to do, such omission could be sufficient for the crime of either murder or culpable homicide, depending on the intention of the accused.”

Thus the question of whether the practice of sedation without hydration or nourishment in terminal care is legal, can only be decided by careful consideration of all the facts in an individual case.

Other matters

WHO SHOULD DECIDE?
Ashby and Stoffell end a rather tortuous paragraph on decision-making at the end of life, with the objection that “It is not the duty of any moral, legal or medical commentator to decide a priori, which treatment may or may not be chosen by a person or his/her substitute health care decision-maker or agent.”

This sweeping statement takes us into the minefield of patient autonomy, and to a consideration of the adverse effects that this can have on a physician’s authority, and on the whole equilibrium of the health care team. The tensions created account for many of the difficulties that dissenting relatives or attendant staff may experience. Such tension will be greatest where life and death decisions are involved. It can also be sensed when a dissenting colleague questions “received wisdom” in the journals! For a philosophical overview on autonomy, see Norden. The nurse/physician authority relationship is explored by May.

From a purely practical point of view there may be no problem if the patient is able to make his or her
views about treatment known. Substitute health-care decision-makers, however, have no legal standing in the UK at present. Problems arise when treatment-limiting decisions must be made for an incompetent patient. The House of Lords Select Committee on Medical Ethics advised that in this situation "decisions should be made by all those involved in his or her care, including the whole health care team, and the family or other people closest to the patient. Their guiding principle should be that a treatment may be judged inappropriate if it will add nothing to the patient’s well being as a person." The principle of necessity referred to above is also pertinent.

I drew attention to the problems that can arise when relatives or members of the health care team request intervention such as hydration, in terminally ill patients. Ashby and Stoffell believe that the sensitivities and consultative processes required to handle such a situation are already embodied in contemporary palliative care practice. I would say that there is much room for improvement and no cause for complacency. Their penultimate paragraph hints at persuasion of the family to accept treatment abatement. One cannot help feeling that anyone who requested active intervention, for any reason, would need to be exceedingly persuasive, determined and articulate to achieve it. The more gentle, flexible and unqualified approach to the family adopted by Dunlop et al is preferable.

THE NEED FOR FORMAL MEDIATION PROCEDURES
Gillon drew attention to the need for some formal mediation procedure in British hospitals and hospices, but little progress has been made on this point. However, there are encouraging signs, in the form of a thoughtful paper on the subject of clinical ethics committees, from the Institute of Epidemiology and Health Services Research in Leeds.

SOME THOUGHTS ON CARE AND COMPASSION
A physician can work for a lifetime with care and compassion without pausing to analyse these sentiments, or read books on the subject. There is an approach to ethics based on care, which some view as hopelessly vague. Some Buddhist and Christian views have been discussed in this journal recently, and are relevant to this debate. The word care itself, is in danger of being devalued, since those who campaign for the right to die in Oregon, USA, see their action as a campaign for compassionate care. No doubt they are motivated by sadness and pity in response to pain and disability, but compassion need not kill. “It is unsafe to encourage or even to allow compassion to see death as its only or prime instrument.”

There is correct compassion and correct care. Anglican and Catholic Bishops refer to the … “Special care and protection” … that the vulnerable deserve … “which provides a fundamental test as to what constitutes a civilised society.” Good medicine involves compassion, but it must be correct compassion leading to constructive action. Doctors should care for the patient supportively and wisely, care for the relatives sensitively, and care for the carers.

Finally there is the legal view of a doctor’s duty to care, some aspects of which have been mentioned already. As the Irish Supreme Court case showed, legal and medical opinions in this area do not always agree. There is clearly a need for doctors, lawyers and ethicists to find more common ground, but standards must not be compromised for political or economic reasons. In the context of the care of the dying it is essential that the law of double effect is honoured, and not abused.

SOME THOUGHTS ON NEEDS
This debate has highlighted the needs of the terminally ill patient for comfort and supportive care, the needs of the relatives, and the need for formal mediation procedures. Doctors and nurses also need to recognise that their own values, attitudes to disability, training and experience will influence their decision-making. Some may consider that there are fates worse than death, but as the Leicester hospice team report, “even a terminally ill patient with incurable malignancy may find life worthwhile and precious.” There is a need for research into the value of maintaining hydration, so that treatment can be evidence-based. At present, as Dunphy et al point out, it may be that a patient’s place of care, whether hospital, hospice or home, is the main factor that determines whether he or she is rehydrated or not.

The view that access to nutrition and hydration is a basic human need, irrespective of the means by which it is delivered is profoundly important. Access to nutrition and hydration determines whether a person lives or dies, whether on a hospital ward, or during famine or war. Decisions about AHA give society, through doctors, considerable power over life and death. Such power must be used with the utmost responsibility.

Summary
This debate has proved valuable. On clinical aspects the responses to date have shown a refreshing willingness by palliative medicine specialists to examine and question their clinical practice. Some have modified certain aspects of their practice but have defended others vigorously. There is some measure of agreement that careful assessment of individual patients is essential, and that some will benefit from rehydration. Hydration can be maintained quite simply using the subcutaneous route in the patient’s home if need be. Legal and ethical discussion has highlighted areas of great difficulty. Consideration of cases such as the Bland case, though necessary, has tended to
deflect attention away from the central issue of the use of sedation without hydration in terminal care. However, discussion has been greatly helped by the deliberations of the House of Lord's Select Committee on Medical Ethics.\textsuperscript{22} They made it clear that it should be unnecessary to consider the withdrawal of nutrition or hydration except in circumstances where its administration is in itself a burden to the patient. Careful consideration of the benefit/burden equation in individual patients is of central importance to patient management.

We all want the dying to depart in peace, in comfort and with dignity. We should all try to ensure that their relatives have peace of mind too. Of course we are not required to “treat the dying as if they were curable”\textsuperscript{95} – but we are required to support life wisely, until it comes to a natural end. That is the whole purpose of this debate.

References and notes


35. See reference 7: 139.
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G M Craig

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have been reopened if the JME had not intervened. I congratulate the JME for taking the bull by the horns — and I congratulate the BMJ for changing its practice and ceasing to send rejected letters on to other authors.

References

OLIVER R DEARLOVE, FRCA
146 The Green, Worsley, Manchester, M28 2PA

Thirst and hydration in palliative care

SIR

I write to correct an error in my recent paper in your journal, and to clarify and expand a point relating to the physiology of thirst.

Author's error: Introduction, line 11, page 147: for six papers, read four papers.

Physiology of thirst: The physiological control of thirst is extremely complex, and my knowledge of it rather rusty. In touching on the subject I have made a statement that is misleading. On page 148 of my paper in the section on “The question of thirst” I wrote: “Does severe dehydration suppress thirst in cancer patients as it does in the healthy elderly?” In fact it is probably not dehydration that suppresses thirst in the elderly, but suppression of thirst that predisposes to dehydration. Phillips et al showed reduced thirst during fluid deprivation in seven healthy elderly men, compared with seven healthy young men. The reason for this was not clear but the authors postulated diminished baroreceptor and volume receptor mediated thirst since levels of the peptide hormone vasopressin, which is linked with osmoreceptors were not reduced. However, certain odd features in the study suggested that cognitive factors were involved, since thirst levels that were suppressed during fluid deprivation, rose during a subsequent “sham” intravenous infusion. Therefore the knowledge that one cannot have access to fluids, may lead to thirst suppression. The important point however is that the combination of dehydration and thirst suppression, whatever the mechanism, is potentially lethal, and could indeed lead to “an escalating spiral of decline”.

In the context of a possible reduction in thirst perception in the dying it is of interest that loss of osmotic thirst has been reported in patients with multiple system atrophy. It is also of interest that opiates play a part in the control of vasopressin secretion, as may prostaglandins. Whether this alters thirst perception I do not know, but clearly morphine and other pain-killers used in palliative care could influence fluid-balance control in unpredictable ways.

References

DR GILLIAN CRAIG
118 Cedar Road East, Abington, Northampton, NN3 2FF