Review paper

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# To feed or not to feed? Clinical aspects of withholding and withdrawing food and fluids at the end of life

## Abstract

The issue of withholding and withdrawing clinically assisted nutrition and hydration (CANH) for imminently dying patients is very contentious. There is no agreement between medical professionals and problem of forgoing CANH is subject of a fierce and sometimes emotional debate.

This paper makes an attempt to examine briefly current clinical evidence on withdrawing and withholding CANH at the end of life. It tries to assess whether it is always beneficial for a patient to provide CANH or whether providing CANH may sometimes cause more harm than good. It also addresses a question whether forgoing CANH for some imminently dying patients is consistent with fundamentals of palliative care. For this reason withholding or withdrawing CANH will be analysed in a context of basic assumptions of palliative care which are presented in the World Health Organisation's definition of this distinctive branch of medicine.

**Key words:** clinically assisted nutrition and hydration, withholding and withdrawing food and fluids, dying

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## Introduction

The ability to take food and fluids and general interest in eating and drinking lessen during a normal process of dying. When a patient becomes too unwell to take food and fluids orally there is a possibility to provide nutrition and hydration by non-oral ways. In this paper, they will be described as clinically assisted nutrition and hydration (CANH) (the term "clinically assisted nutrition and hydration" was recently introduced in the United Kingdom by new General Medical Council guidance *End of life treatment and care: Good practice in decision-making* [1]. The new term is used instead of "artificial nutrition and hydration or tube feeding". This subtle change means that nutrition and hydration provided by tube is treated not as "artificial" but rather "assisted" by clinical means).

Withholding or withdrawing CANH for patients at the very last stage of their lives, i.e. when death is imminent and expected in days or hours, raises many concerns. They are raised not only by the public, ethicists and patients' families but also by medical professionals. Interestingly enough, medical opinions on the issue are divided. However,

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there is a common agreement among clinicians that more research is needed as medical evidence is not unequivocal [2, 3].

Food and fluids are commonly regarded as a basic care. Eating and drinking are fundamental human needs and their significance is commonly accepted. They carry numerous social, cultural and religious connotations. That is why not providing CANH is often believed to be an equivalence of depravation of food and water resulting in starvation and dehydration and intuitively may be perceived as cruel and inhumane.

Indeed, benefits, burdens and risks involved in the provision of CANH at the end of life are often not clearly understood. Attitude towards non-oral nutrition and hydration is sometimes shaped by deeply rooted convictions, misperceptions and misunderstandings. That is why, the exploration of clinical aspects of forgoing CANH is of a great importance for the best interest of a patient and good communication and relationship between patients, their families and healthcare professionals.

## The World Health Organisation's (WHO) definition of palliative care

According to WHO [4] palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness. It is done mainly through the prevention and relief of suffering by means of early identification, impeccable assessment and treatment of pain. Other problems — physical, psychological or spiritual should be also addressed. To achieve this palliative care (among other things):

— provides relief from pain and other distressing symptoms;
— affirms life, regards dying as a normal process and intends neither to hasten or postpone death;
— offers a support system to help the family cope during the patients illness and in their own bereavement.

## Palliative care provides relief from pain and other distressing symptoms

There is conflicting evidence with regard to links between end of life symptoms and presence of food and fluids deficits in imminently dying patients. On one hand many studies have found high symptom burden when nutrition and hydration were provided. On the other, there were also studies which have not confirmed this.

This ambiguity shall be treated seriously. The most important questions from the clinical point of view are as follows: whether not providing CANH at the very end of life may be a cause of distressful symptoms for patients, whether provision of nutrition and hydration can prevent or alleviate them and whether provision of CANH may cause additional harm to a dying patient. These questions will be analyzed below.

### Relief from pain and CANH

There is evidence that as a result of a terminal dehydration (it is important to distinguish patients whose fluid replacement is medically indicated. This type of dehydration will cause a more rapid deterioration, usually over days, in the setting of a sudden cause suggested by the history, e.g. polyuria, polydipsia with hypercalcaemia, vomiting from bowel obstruction, diarrhoea, medical examination and laboratory tests. These acute changes are different from changes in dying patients where dehydration — called terminal dehydration — occurs gradually, takes weeks/months — with accompanying symptoms such as weakness, fatigue, weight loss and drowsiness [5]. A body produces ketones and other metabolic substances. They have natural anaesthetic effect for the central nervous system and cause a substantial decrease of patient's suffering [2, 6]. There is also a concentration of opioids and increased production of natural endorphines in a human body at the end of life. This also reduces pain and therefore a need for analgesia is decreased [7]. Anesthetic property of natural terminal dehydration is emphasized also by some clinicians [8, 9]. The fact that terminal dehydration usually is not painful for a patient needs to be stressed [3]. Moreover, a provision of CANH itself may be a cause of additional pain for a patient [10].

However, the anesthetic effect of terminal dehydration may be also linked with drowsiness and cognitive impairment due to an accumulation of opioid metabolites. For some patients it may be beneficial, but others may wish to be as conscious and alert as it is possible. As dehydration is known to cause confusion and restlessness, it may also add to renal failure and thus leads to accumulation of opioid metabolites (resulting in confusion, myoclonus, and seizures) [11, 12]. To avoid these symptoms, it may be sometimes desirable to provide clinically assisted hydration (CAH). There are studies which have confirmed benefits of hydration for that purpose [13, 14].

### Secretion and CANH

During the dying process body fluids level decreases. This leads to reduced gastric and pulmonary secretions. Therefore not providing CANH for dying patients decreases nausea and vomiting together with alleviation of other symptoms like coughing, choking, congestion and rattle [2, 6, 7]. As these symptoms are very common, annoying and disturbing for dying patients, their alleviation is crucial. Study led by Morita (considered to be the largest and the first multicenter observation of the issue) was conducted to investigate an association between hydration volume, dehydration and fluid retention symptoms in cancer patients at the end of life. It revealed that other symptoms connected with fluid overload like peripheral edema, ascites and pleural effusion were more likely to worsen in the last 3 weeks of life if CAH was provided [15]. The study also suggested that the overall benefits of active hydration therapy are limited by the possibility of aggravating fluid retention symptoms [15, 16].

### Relief from delirium and CANH

Delirium is a common symptom experienced in the last days or hours prior to death [17]. That state which consists of deficits in cognition and awareness together with behavioral disturbance and changes in psychomotor activity is often a source of a severe distress for both patients and their families [18–20]. Most notable impacts of delirium on a patient are hallucinations and other perceptual disturbances, confusion, disorientation and agitation [21]. It is recognized that delirium has multiple causes, for instance hypoxia, organ failure, medications such as opioids, and — what is important in the discussed case — fluid and electrolyte imbalance [2].

Several trials suggest that hydration may be beneficial in preventing and managing already existing delirium [17, 22]. However, these studies were related to terminally ill patients and elderly people (but not imminently dying). In those cases acute and treatable dehydration was an etiology of delirium, unlike gradual dehydration related to the dying process.

It is important to balance possible benefits and burdens of hydration as rehydration might exacerbate patient distress and worsen other symptoms, such as peripheral edema and bronchial secretions. It is also recommended not to overlook treatable dehydration, especially in pre-terminal patients (as dehydration and accumulation of opioid metabolites can accelerate agitated delirium) and consider provision of hydration in this situation [23].

Clinical evidence related to management of delirium at the end of life is divided. Some studies do not recommend hydration for dying patients as they show that there are no benefits of administration of fluids to tackle with terminal delirium [15, 26, 27]. Other studies found that hydration may be helpful to control terminal delirium as provision of CAH prevents confusion, agitation, neuromuscular irritability, neurotoxicity and reduces the frequency of hallucinations that may occur as part of delirium or independently [13, 14].

### Relief from hunger

Prima facie one may think that deprivation of food may cause harm to a dying patient and in consequence lead to his premature death. In this case death, may be argued, would be a result of starvation rather than incurable, terminal disease. However, patients at the end of life (particularly with advanced cancer) appear to be malnourished, but that kind of malnutrition is different from starvation in an otherwise healthy person [26]. It should be stressed, that there is no evidence that nutritional support brings a material relief to dying patients. On the contrary, there is evidence that nutrition can cause a tumour to grow, and thus increase its local symptoms [5].

As Saunders said when countered attacks on hospice rules on nutrition and hydration: "(…) [patients] do not die of starvation (…). They die of a running-down of all systems: to institute intravenous feeding and hydration is likely to add neither to the length nor to the quality of remaining life, but only to discomfort" [27].

Nonetheless, some people worry about the fact that their dying loved ones experience hunger. They perceive forgoing CANH as synonym of adding sufferings to the last moments of patients' lives. However, several studies confirm that patients at that stage generally did not experience hunger. Those who did had it very reduced and needed only very small amounts of food for alleviation [28–30].

### Relief from thirst and dehydration

Thirst and dehydration are amongst the most often raised concerns regarding administration of CANH for dying patients. There is no agreement between medical staff, ethicists and patients' families.

A sensation of thirst, relatively more frequent in comparison with already discussed hunger, is seen to be a nonspecific symptom which does not correlate with hydration status of dying patients [28].

Interestingly enough, thirst and symptom of dry mouth are often not differentiated by patients. Terms are usually used by them interchangeably. One of the crucial and the most cited study shows that symptoms of thirst/dry mouth "were completely relieved with ice chips, sips of liquid, lip moisteners, hard candy, and mouth care" [28]. These measures deliver far less fluid than is required to maintain hydration balance. It was confirmed by another study which showed clearly that administration of fluids is not more beneficial than mouth care [24].

It is worth noticing that another large survey demonstrates that deterioration of thirst and other fluid retention symptoms (for instance oedema, ascites) together with limited benefits in relieving those symptoms were frequently observed in dying patients receiving intravenous hydration [31].

As far as dehydration is concerned, several studies have found that in case of imminently dying patients there is no connection between decreased fluid intake and biochemical blood parameters indicating dehydration (unlike a situation of acute dehydration) [28, 32–34]. Some argue on this basis, that terminal dehydration does not make harm to dying persons. Moreover, they claim that applying CAH may cause harm [2, 3, 6, 35].

However, there are also other standpoints. Craig, a consultant geriatrician, claims that dehydration of patients at the end of life can lead to circulatory collapse, renal failure, anuria and premature death. She accuses palliative medicine of applying sedation in order to mask unpleasant effects of dehydration [36]. Craig believes that every patient, no matter how ill, should have a right to receive water, and that right should be protected by the law [37] (she is not alone in this view. Rosner claims that food and fluids should always be provided — no matter if given orally or "artificially". He describes nutrition and hydration as a "supportive care" which should be given "until the very end". That duty may be released only at the request of a patient [38]). It seems that she does not accept that terminal dehydration at the end of life has a different aetiology than dehydration in general.

As Dunlop points out in a response to Craig's arguments, the symptoms of dehydration in an otherwise healthy person are thirst, dry mouth, headache, fatigue, cognitive and renal impairment. The situation of dying patients, Dunlop argues, is completely different from acute dehydration of patients who have correctable causes for their deterioration. Dying patients' symptoms such as fatigue and drowsiness usually occur earlier than cessation of food and fluid intake and it is a gradual process [5].

It is of vital importance to distinguish between acute dehydration from reversible causes and terminal dehydration at the end of life. While provision of hydration for acute, correctable causes should be provided for symptom relief, the situation of imminently dying patients may be different. Dehydration at the last stage of life may be not distressful and CAH may be not required, providing that adequate mouth care is given [39].

Ashby, in other response to Craig's arguments, emphasizes that the aim of sedation is to alleviate patient's suffering and emotional distress for which other interventions have failed. "But it is not deemed necessary to hydrate sedated patients during the dying process when they are unable to maintain oral intake, as it makes no sense to attempt to treat a transiently reversible component of their overall dying process" [40].

In short, not providing CAH should not be automatically viewed as a deprivation of fluids leading to dehydration and subsequently to death. It should be rather perceived in a context of a fact that the patient is dying and his needs for hydration are decreased [41]. However, some patients may well benefit from hydration. That is why every person's need for fluids provision should be assessed carefully and individually.

## Palliative care regards dying as a normal process and intends neither to hasten or postpone death

Palliative care regards death as a natural end of life and accepts it. In situation when death is inevitable all possible efforts are made in order not to prevent death but to make it as much comfortable as possible. It implies finding a balance between fighting for life and allowing death to occur.

It is a common belief that nutritional support makes patients stronger and as a consequence increases their chances for survival. Thus, some may argue, depravation of food and fluids hastens death of patients approaching the end of life. Possible beneficial effect on prolongation of life was considered as a major reason that some patients and their relatives would choose application of CANH [42, 43].

Interestingly enough, the belief that CANH prolongs life is one of the most prevalent misperceptions. There are no studies that would support these

assumptions [35, 44, 10]. For instance, a large, prospective, multicentre study which examined effects of nutritional supplementation on survival in seriously ill hospitalized patients, demonstrates that there is no association between prolongation of life and CANH. Moreover, CANH was associated with decreased survival of patients with multiorgan system failure, chronic obstructive pulmonary disease, acute respiratory failure, sepsis and cirrosis (improved survival was associated only with permanently comatose patients) [45].

Some argue that although CANH does not prolong life, there is no reason for not providing it because CANH does not prolong dying process as well (a belief that CANH prolongs process of dying and interfere with an acceptance of a terminal condition is raised by some opponents of CANH at the end of life [2]). There is another important argument of proponents of CANH for dying patients, namely that providing food and especially fluids fulfills a basic human need. Despite the fact that CANH does not prolong life, it is argued that fluids should be given as a minimum standard of care [12, 46, 47]. In this context a principle question is whether CANH may cause harm to patients at the end of life. In the light of clinical evidence which was presented above the answer might be positive. It appears that it is not always advisable to provide CANH.

Another crucial and relevant issue is connected with a possible patient's refusal to receive food and fluids. Not providing CANH is seen by some thinkers [48, 49] as a legally available method of voluntary death. A kind of alternative to physician assisted suicide (PAS) and euthanasia. It is sometimes believed that by forgoing food and fluids in case of terminally ill patients it is possible to pursue hidden form of euthanasia.

This viewpoint should be addressed very seriously, as palliative caregivers must not allow to be manipulated by euthanasia advocates. It is important to emphasize that a fundamental basis of a palliative care is acceptance of the death as a natural process. Palliative care has no intention neither to hasten nor postpone death. There is no space for physician assisted suicide and euthanasia in palliative care. Any comparison of not providing CANH to imminently dying patients (justified by an acceptance of imminent death and with the intention of making the process of dying as much comfortable as possible) to PAS or euthanasia (where death is hastened, intended and consciously induced) is an unacceptable abuse and a manipulation.

## Palliative care offers a support system to help the family cope during the patients illness and in their own bereavement

A patient's family is a subject of palliative care and support as well. This approach, so specific and distinctive for this branch of medicine, has particular implications. Patient's family play an important role and should be always taken into account. Good practice of palliative care suggests that decisions about providing (or not) CANH should always involve also patient's family and carers [50].

Some studies show that families and carers experience substantial distress caused by lack of a provision of CANH to a patient [51, 52]. As food and fluids are regarded as something very basic and essential for patient's comfort, not providing it is treated as abandonment of care and contribution to patient's deterioration. In one research families' comparisons of dehydration to a situation of a person dying because of thirst in the desert were not rare [51].

Apart from the medical issues connected with CANH, it is essential to remember the significance of food and fluids from a symbolic and psychological point of view [3]. They are perceived as synonyms of life, compassion and nurture. Feeding the patients makes families feel useful. All these concerns need to be carefully listened and palliative care specialists need to give a decent attention when dealing with them. An open discussion and education of the family are of a crucial importance.

In this context it is good to remind Saunders wise words that "(...) it is important that neither staff nor families should feel guilty where the natural process of dying from an irreversible terminal condition is taking place" [27].

## Conclusion

It is beyond a reasonable doubt that death from absent of nutrition and hydration is distressing and painful for a patient. However, the situation at the very end of life, i.e. when patient is dying from life-limiting illness or as a result of general frailty in old age and running down of all systems, is completely different. In the latter case, a patient is not dying because of failing to provide nutrition and hydration. He is dying and that is why he is not eating and drinking.

At the end of life a patient's desire for food and fluids significantly decreases and this is a normal

and integral part of the dying process. That is why, it is of a pivotal importance to distinguish those who are diagnosed with a life-limiting illness and/or are expected to live for weeks or months from those who are approaching the end of life, i.e. when death is anticipated in days or hours. What would be not acceptable for the first group may be fully permissible for the second one.

On one hand, it appears to be justified to state that provision of CANH for imminently dying patients who are failing to take food and fluids at the last stage of their lives, providing that the diagnosis has been made carefully and any identifiable and potentially correctable causes were excluded, is unlikely to confer material benefit. Therefore withholding or withdrawing CANH at the very last phase of a human life may be permissible and sometimes even desirable. On the other, CANH can bring benefits to some patients when administered in appropriate circumstances (but everyone involved in a care of a patient must be conscious that CANH can also cause harm).

In this context, a careful clinical assessment, diagnosis and regular evaluation of every individual situation cannot be overestimated. Healthcare professionals must be prepared to make genuine and unprejudiced assessments of a relevance of CANH to each patient. Taking into account the risk of misdiagnosis (no matter how small) and that clinical evidence is not unanimous and clear-cut, there cannot be any general and arbitrary rules whether CANH should or should not be provided. It is reasonable to recommend that in case of any doubts, CANH may be considered on a trial basis in order to allow a clearer assessment to be made. During this period it should be evaluated whether it is beneficial or burdensome to a patient.

An integral part of the decision making process related to provision or forgoing CANH is communication with the patients and/or those close to them. All expressed concerns need to be carefully listened. Healthcare specialists are expected to give a decent attention when addressing doubts, give weight to the patient's wishes and values. An open discussion and explanation of the benefits, burdens and risks of providing CANH are of a crucial importance.

As it was presented above, an issue of withholding or withdrawing CANH at the last stage of life is still rather contentious. Nevertheless, forgoing CANH in situations considered to be beneficial to a dying patient, appears to align with assumptions of palliative care.

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