European Geriatric Medicine 6 (2015) 87–90

Available online at
ScienceDirect
www.sciencedirect.com

Elsevier Masson France
EM|consulte
www.em-consulte.com/en

Ethical issues in clinical practice

Feeding and hydration in terminal stage patients

J.-M. Ribera-Casado

Universidad Cumplutense (Departamento de Medicina), c/Joaquín María López 68, 28015 Madrid, Spain

ARTICLE INFO

Article history:
Received 29 September 2014
Accepted 22 November 2014
Available online 31 December 2014

Keywords:
Feeding
Hydration
Terminal stage
Ethics
Dementia
Enteral tubes
End of life

ABSTRACT

The aim of this paper is to present and discuss some recent publications and consensus documents about feeding and hydration in terminal stage patients. First part includes a review since the framework of bioethical problems where these topics may be included. Next point is focussed on a short presentation of some evidences base clinical trials. Finally, in the last part, it is offered information about the most relevant guidelines and consensus documents published along last years. As conclusion, we see that evidence base informing clinical decision-making about artificial hydration in the dying patient is sparse and solutions must be adopted on individual basis. Mental capacity of the patient is one of the most important pillars to take into account. It is important, also, to have good information about the most frequent doubts that patients and relatives may set up.

Among the bioethical end-of-life-care challenges that may find a physician, the decision to interrupt feeding and/or hydration is one of the most complex and difficult to take up (Table 1). It is a complex and controversial matter. Geriatricians are one of the medical collectives frequently involved in these situations. The aim of this paper is to present and discuss some recent publications and consensus documents about these topics.

1. The scope of the problem

There is a vast amount of ethical questions that can crop out at the end of life. Forty years ago F.J. Ingelfinger [1], who was editor of *New England Journal of Medicine*, said about the sentence "Death with dignity" that "as long as society demands the care that scientific medicine can offer, it is a deception to pretend that the process of dying can be invested with dignity; the most a doctor can do–and should do–is to mitigate the indignities that the patient must bear"; an opinion I consider valid nowadays. In this context, it is probable that the primary goal of end-of-life-care is to get the best possible degree of patient's comfort, with a good control of pain and other symptoms, including those related to hydration and nutrition [2].

Whenever any of these questions arise, before taking any specific decision we must always take into account four main bioethical principles:

- autonomy: respect to his (her) code of beliefs. It includes information about if has the patient signed an advanced directives document;
- beneficence: meaning that the predicted benefit must always outweigh the predicted risk;
- nonmaleficence: to avoid useless or futility information or treatment;
- justice: the best possible care with available resources. All these principles must be applied to problems such as withdrawal of active drug treatments including antibiotics, and, also, of course, the specific appropriate decisions relatives to feeding and fluids.

Death, in our current XXIst century, often occurs slowly in old age, at the end of a chronic life-limiting illness. The protagonist usually is a woman rather than a man, over 80 years of age, with advanced organ failure established, most of two chronic or degenerative condition, with many personal concerns, and likely with some degree of confusion; with a lot of relatives and/or friends around him/her telling the doctor what he/she should do.

Many young physicians are scarcely prepared to confront these situations. In most cases, they have no specific preparation in this field, but she/he must understand that the problem is impossible to avoid; and she/he plays a double role, the one lived by her(him)self

E-mail address: jribera.hcsc@salud.madrid.org

http://dx.doi.org/10.1016/j.eurger.2014.11.009
1878-7649/

Table 1
Most frequent bioethical problems related with "end-of-life-care".

Information, how much? when? how to deliver it?
The question of pain, physical and psychological
The place of death: at home?, in a hospital?, in a nursing home?
Religious attendance
Nutrition and hydration
"Do not resuscitate" orders and eventual presence of advanced directives
The question of "Death with dignity"
Aspects related with euthanasia and assisted suicide

and the one assigned by "others". Previous experience is very important. The dying process is often extremely stressful for families to observe. In these cases, physicians behave as an orchestra conductor trying to integrate care; while people around him/her critically look at what they are doing. Solutions must be established on individual bases and there are no simple answers because we must play with a large number of variables and it is necessary to establish priorities and possibilities.

Before any decision is taken, the first obvious point is to be sure that the patient is really a "terminal one", and this is not always easy. Thereafter to collect a careful and detailed medical record, as well as to select which are the main medical and ethical problems, and, to find out if a document with advanced directives exists. It is mandatory, of course, to be sure that the main actor (the protagonist) is the patient, and not any other person or institution. When it appears that the patient is dying with no reversible cause, the aim of clinical care must be to maximize the patient's comfort, what includes attention to his/her state of hydration and nutrition.

2. Evidences base clinical trials. A short, non-systematic review

Clinical evidence-based data derived from specific published studies about hydration and nutrition are scarce. In fact, it is difficult to know the patient's preferences about the different matters to consider because we have no much validated information on these topics. One paper [3] based on an open questionnaire to elderly patients with cancer or non-terminal cardiopathy, asked about what they considered a good or bad death. It includes questions related to symptoms, quality of life, and possible (scenarios intensive) care units, acute wards, nursing homes, etc.. There are a great heterogeneity in answers and no differences according with specific type of disease. Thus, authors remark the importance of individualise each situation.

In another paper [4], the authors compare actual treatments with patient's preferences on starting or forgoing treatment at the end of life. They select two representative cohorts of:

- the older Dutch general population, and;
- people with known advanced directives. Questions analysed included: resuscitation, artificial nutrition and hydration, use of antibiotics, and artificial respiration. In conclusion, there was a high concordance between preferred and actual treatment in those patients who preferred treatment but a lower one in people who did not it. In this case, these authors emphasize the importance of asking patients about their preferences.

Moreover, a recent international survey searched for empirical studies published between 1985 and 2010 relating to attitudes and knowledge regarding clinically assisted hydration (CAH) in the care of dying patients [5]. Three core themes emerged in these publications:

- the symbolic value of hydration;
- the question of beliefs and misconceptions, and;
- the big differences derived of cultural, ethics, and legal ideas about hydration. In this case, the authors conclude that there was little robust evidence about the perceived value of CAH in the last days and hours of life.

In a cross-sectional, representative online survey [6], the strongest determinant of prescribing patterns was an agreement with the clinical/psychological efficacy, and the decision to prescribe or withhold were largely based on clinical perceptions. Another documented review about nutrition in the acute phase of critical illness also includes recommendations in specific clinical situations [7]. This review concludes that controlled trials have not generated unequivocal evidence that feeding protocols targeting full-replacement nutrition early in the course of critical illness results in clinical benefits. Authors suggest to limit the number of nutritional interventions that can be confidently recommended for daily critical care practice. Hence, it seems reasonable to initiate some gastric feeding, while also providing micronutrients, once the patient's condition is stabilized and to allow hypocaloric macronutrient intake during the first week of critical illness, but have never done it before. Whether patients with pre-existing malnutrition should be treated differently is uncertain. From the point of view of these authors, new insights limit the number of nutritional interventions that can be confidently recommended.

The positive effect of hydration in terms of survival is clearly questionable. One of the few studies in this field was conducted by Bruera et al. [8] over 129 terminally ill patients with advanced cancer. In a randomised, placebo-controlled, double blind trial, they did not find any advantage in terms of survival when used 1 litre/4 hours of normal saline subcutaneously per day in moderately dehydrated patients compared with placebo (100 ml) over 4 hours every day. The same happened in another similar study [9] carried out in a palliative unit, analysing hydration and nutrition.

Terminology is, of course, important because in some countries the physician assisted suicide is not legal though there are not legal restrictions to stop eating and drinking. This question is treated in a recent paper [10] that opens a dilemma asking if to talk about continuous sedation until death and physician assisted death are word games or war games. Arguments pro and against refer basically to the same ambiguous themes: intention, proportionality, withholding artificial nutrition and hydration, and removing consciousness. Authors think that this debate is first and foremost a semantic rather than a factual dispute, with prevalent ambiguity. So, voluntary refusal to food and fluids has been proposed as an alternative to physician assisted suicide for terminally ill patients who wish to hasten death. Some studies analyse the eventual consequences of this decision. It was the case of a questionnaire to all (429) nurses employed by hospice programs in Oregon (US) [11]. There were 72% of responders and one third of them reported that in the previous four years they had cared for a patient who deliberately hastened death by voluntary refusal of food and fluids. The main conclusions of this study was that on the basis of reports by nurses, patients in hospice care who voluntarily chose to refuse food and fluids were elderly, no longer finding any interest in living, and usually died a "good" death within two weeks after stopping food and fluids.

A particular problem is posed in the case of older people with a diagnosis of advanced dementia [12]. Many of these patients develop difficulties with eating and drinking during the course of the disease. Advanced dementia should be seen as a terminal illness. Different reviews conclude that feeding tubes may cause more suffering than comfort, and that it can also cause complications such as aspiration. Accordingly, a large Cochrane survey about this question evaluated the outcome of enteral tube nutrition for older people with advanced dementia who developed