

EDITORIAL

Nutrition in the terminal stages of life in nursing-home patients

The research group headed by van der Wal and van der Maas was the first to carry out large-scale studies on euthanasia, physician-assisted suicide and forgoing artificial administration of food and fluids at the end of life [1, 2].

For many physicians outside The Netherlands, being a pioneer in this field of science may seem a dubious honour—but, without detailed analysis of medical practice with regard to end-of-life decisions, we would still be in the dark. The Dutch government has been courageous and far-sighted in funding empirical studies on end-of-life decisions. These were orchestrated successfully by this research group, thanks to the conscientious participation of many Dutch physicians. The stimuli to these studies were the introduction in parliament of Dutch bills or laws, and also clinical incidents and disputed end-of-life decisions.

Justification for end-of-life research

Several cases have recently received much attention in the Dutch press. One incident concerned an old man who did not receive enough food and fluid during a period of illness in a Dutch nursing home. This case may have prompted the research carried out by Onwuteaka-Philipsen *et al.*, reported in this issue of *Age and Ageing* [3]. The researchers present unique and important data from research on a large sample of nursing-home patients and a sample of nursing-home physicians, which describes the practice of withdrawing and withholding artificial administration of food and fluid.

Why are these data so important? First, because reliable data on this subject are sparse. Secondly, they give us some idea about the reasons and the context of decisions to forgo nutrition and fluids in nursing-home patients. Thirdly, these findings should stimulate national and international discussions among physicians, nurses and managers working in nursing homes, as well as among geriatricians, politicians, and patients and their families. We hope that this debate will result in practical guidelines.

Data reflecting reality are a *sine qua non* for a fruitful discussion on a topic previously based on experience, prejudice, moral values and beliefs, and legislation. The price the Netherlands has to pay for this unique

research is that we are now less renowned for our clogs and tulips than for our policy on end-of-life decision-making.

Findings and limitations of the study

Onwuteaka-Philipsen and colleagues' postal interviews showed that 23% of deaths in Dutch nursing homes are preceded by withdrawing or withholding artificial fluid or food. Altogether, these decisions about administration of artificial fluid or food constitute 36% of all end-of-life decisions in nursing homes. Withholding or withdrawal of artificial fluid or food is more often practised in incompetent patients than competent patients (40% *vs* 27%). However, the methods used to assess incompetence were not formalized in this study. In competent patients, decisions about administration of artificial fluid or food almost always (98%) followed in-depth contacts between physicians, elderly subjects and their children. Only 11% of incompetent patients were involved in decision-making. Coma, being probably the only good reason not to discuss withdrawal of artificial fluid or food with an incompetent patient, was present in one-quarter of incompetent patients.

The main findings from the end-of-life interview study are that more than half of nursing-home physicians practised withdrawal or withholding of artificial fluid or food, more often in incompetent patients. Actually withdrawing enteral or parenteral nutrition was practised only by a minority of nursing-home physicians (5 and 25% of those who took decisions about artificial fluid or food in competent and incompetent patients, respectively).

The nursing-home physicians interviewed hypothesized that their decisions about administration of artificial fluid or food had not shortened life to any great extent. They estimated that 60–70% of the patients would have died within the same week without withholding or withdrawing artificial nutrition. However, valid ways to estimate time left for terminal patients are not available. Doctors in general are over-optimistic in estimating their terminal patients' life expectancy, especially in cancer patients [4]. However, non-oncological specialists tend to be overpessimistic

in estimating the survival in hospice patients. Thus, these estimates are probably biased in this study, too.

Low quality of life of these patients (40–60%), as judged by the responsible physician, was the initial reason for introducing a decision on administration of artificial fluid or food. However, it is not clear how quality of life was judged, and no formal instrument was described. It is notoriously difficult to assess quality of life in geriatric medicine, especially in elderly patients with cognitive impairment.

Withholding nutritional support (i.e. not starting artificial nutrition in patients for whom an indication for this support was present) was far more common than withdrawal. Crucial in withholding decisions (but not elaborated by Onwuteaka-Philipsen *et al.*) is how to decide about the indication for artificial nutrition in elderly people with only a short life expectancy. We will briefly review the evidence for this.

Artificial nutrition near the end of life

Finucane *et al.* reviewed data on the effects of tube-feeding in patients with advanced dementia [5]. Their conclusions were that it did not reduce the risk of aspiration pneumonia, that it was unclear whether tube-feeding prevents the detrimental consequences of malnutrition, that there was no reduction of the risk for pressure ulcers or infections in general and, finally, that there was no overall prolongation of survival in demented patients with dysphagia. They found no data to suggest that tube-feeding might improve functional status or comfort in these patients. In short, there is no evidence to justify tube-feeding in severely demented patients. This probably means that, for most nursing-home patients, for whom one might think that there is an indication for artificial nutritional support, there is no evidence-based indication. Therefore, the use of the term ‘withholding’, which has a morally negative connotation, is not justified in these cases.

One could argue that there is also no indication for tube-feeding in non-demented nursing-home patients at the end of their lives. Due to a lack of evidence for the indication of nutritional support for mentally competent elderly nursing-home patients, we still have to rely on data from non-nursing-home patients with end-stage chronic disease (e.g. cancer and stroke patients). For example, a randomized study in patients with small cell lung cancer who either received a month of parenteral feeding at the start of chemotherapy or no nutritional support, not only failed to provide benefit, but was associated with greater risk of infection [6]. Reviews on the evidence of nutritional support in end-stage cancer patients support these findings [7].

Recent studies on nutritional support in terminal patients with wasting diseases (such as end-stage chronic

obstructive lung disease) have not shown any benefit [8]. Winter concluded that there is no evidence that nutritional support prolongs life or decreases morbidity in patients with cancer, sepsis or advanced cardiac or respiratory disease [9]. Conversely, there is no hard evidence that withholding or withdrawing food or fluid is either beneficial or harmful. This is primarily because research on nutritional support in the later stages of life can only be carried out with studies using less rigid designs. (Randomized controlled trials, for example, are not appropriate.)

However, the available data suggest that terminally ill patients without nutritional support do not experience troublesome hunger or thirst, and that small amounts of food and fluid and good mouth care are sufficient for alleviation of dry mouth or slight hunger [10]. Moreover, diarrhoea, urinary incontinence and respiratory secretions, which are often uncomfortable in the terminal stages, diminish without nutritional support. In sum, withholding nutritional support may often be a misnomer for not starting artificial nutritional support.

Conclusion

Returning to the study in this issue of *Age and Ageing*, we now have data on the number and the type of patients in whom nutritional support is withheld or withdrawn in Dutch nursing homes. When these end-of-life decisions are carefully thought out and accompanied by good communication with patients and family, we have shown that they are in agreement with the lack of evidence for beneficial effects of nutritional support in terminal stages of life. These decisions about withdrawal or withholding of artificial fluid or food are also in line with national and international guidelines on this topic [11].

The authors deserve credit for clarifying medical decision-making on nutritional support in nursing homes at the end of life, which until now could only be debated based on experience, moral values and prejudice. The Dutch government is to be congratulated for facilitating this research, at the risk of being accused of being the European Oregon. However, there is still much work to be done.

More quantitative studies are needed which focus on other decision-making strategies at the end of life, both in nursing homes and in hospital. It is, for example, not known how often extreme withholding of nutritional intake (physician-stimulated self-starvation) occurs [12]. Qualitative studies are needed to clarify to what extent care at the end of life is well organized, as described by Loewy [12]. Future work on terminal nutrition should be broadened to include the optimal use of natural feeding in alleviation of common complaints of terminal disease and in the improvement of communication between elderly patients with a short life expectancy and their family and carers.

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