Withholding the artificial administration of fluids and food from elderly patients with dementia: ethnographic study

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Abstract

Objective To clarify the practice of withholding the artificial administration of fluids and food from elderly patients with dementia in nursing homes.

Design Qualitative, ethnographic study in two phases.

Setting 10 wards in two nursing homes in the Netherlands.

Participants 35 patients with dementia, eight doctors, 43 nurses, and 32 families.

Results The clinical course of dementia was considered normal and was rarely reason to begin the artificial administration of fluids and food in advanced disease. Fluids and food seemed to be given mainly when there was an acute illness or a condition that needed medical treatment and which required hydration to be effective. The medical condition of the patient, the wishes of the family, and the interpretation of the patients’ quality of life by their care providers were considered more important than living wills and policy agreements.

Conclusions Doctors’ decisions about withholding the artificial administration of fluids and food from elderly patients with dementia are influenced more by the clinical course of the illness, the presumed quality of life of the patient, and the patient’s medical condition than they are by advanced planning of care. In an attempt to understand the wishes of the patient doctors try to create the broadest possible basis for the decision making process and its outcome, mainly by involving the family.

Introduction

Withholding the artificial administration of fluids and food, especially in incompetent patients in nursing homes, and the benefit of such practice in patients with advanced dementia are both well debated topics. We aimed to determine the decision making process behind withholding the artificial administration of fluids and food in incompetent patients.1

Methods

Our qualitative, ethnographic study was conducted in two phases.2,3 The first phase (October 1998 to April 1999) was carried out by RP in a nursing home (201 beds) in a rural part of the eastern Netherlands. The second phase (December 1999 to February 2001) was carried out by AT in a nursing home (210 beds) in the more urbanised western Netherlands.

For 7 months RP investigated the practice of withholding the artificial administration of fluids and food by the staff. The time frame was too short to understand decision making when illnesses had longer trajectories, and the attitudes of the other professionals were not sufficiently clear. The study period for phase 2 was therefore increased to 14 months, on a part-time basis, 3 days a week. Owing to media attention surrounding the practice of withholding the artificial administration of fluids and food, the staff of both nursing homes were initially conscious of the researchers. The researchers observed but did not participate in the decision making process. The findings and conclusions were submitted to the participants and discussed in formal interviews conducted at the end of both phases.4

Overall, 35 of the patients (28 women) were candidates for the withholding of the artificial administration of fluids and food. Their ages ranged from 61 to 98 years. Eight doctors, 32 families, and 43 nurses were observed in the decision making process.

Analysis

Our analysis and results are based on four types of data: comprehensive notes made by the researchers; formal interviews (taped and fully transcribed); medical and nursing records; and a diary kept by the researchers of their own behaviour and attitudes.
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Data were analysed per patient by both researchers, resulting in 35 case studies. These were read repeatedly to identify patterns. The cases studies were then compared for similarities and differences between topics analysed. Saturation of data was reached after 21 cases; the identified patterns were checked with the last 14 cases.

Results

Advanced planning of care

The family was involved from the moment a patient was admitted to the nursing home. This was achieved by holding regular meetings, starting shortly after admission, in which the deterioration and subsequent management of the patient were discussed (see bmj.com). Often these conversations resulted in policy agreements, which were recorded in the patient’s notes. Few patients had a written living will; in specific situations they did not want their life prolonged or wanted euthanasia. These wishes were recorded.

Illness processes

Trajectory 1: the slow downward curve

When dehydration resulted from dementia there was hardly ever a decision to give fluids and food artificially. Slow deterioration was considered a natural course of the disease, in which patients would not benefit from the artificial administration of fluids or food. Patients were, however, given other types of non-medical support, including special dietary provisions, and extra attention was paid to the way food was given. Care depended largely on the nursing staff.

Mutual agreement usually existed between caregivers and family not to prolong the patient’s life unnecessarily, because it was considered that hydration would not improve the quality of the patient’s life (box 1).

Trajectory 2: the interruption

Acute illness such as an infection or depression often interrupted the slow deterioration from dementia (15 of 35 cases). This accelerated deterioration was usually considered to be reversible and medically treatable.

Box 1:Conversation with the family about the onset of advanced dementia

Doctor L: We’ve been able to keep that up for some time, but there’s not really much more that we can do. And, in spite of everything, she continues to lose weight. It’s not yet necessary, but the next step is to decide whether we are going to feed her artificially. Mrs JS’s son in law: Through a tube? Doctor L: For instance. But the question is is that the right thing to do, and is it going to help her? Mrs JS’s daughter: No. My mother would never have wanted that. She always said that she didn’t want to be kept alive. No, no tubes.

Doctor L: That’s exactly what we think. If we thought that we would be helping your mother, for instance to get over a temporary lapse by feeding her artificially, we would certainly consider it. That was the case last year, when we gave her antibiotics because she had pneumonia. We also gave her a hypodermoclysis because she was dehydrated and the antibiotics would otherwise have been ineffective. She improved a lot after that. At least we think that she did quite well last year. But now we’re faced with a different situation. Now the dementia has progressed, and there is no way of stopping it. We can try to slow down the process, as we have done by spoiling her, giving her all kinds of supplements in her food, and the treatment we gave her last year. But there comes an end to that process. Your mother is getting towards the end, and that’s what we feel is happening now. This is the last phase that we are approaching—the phase of withering away.

Mrs JS’s daughter: We can see that too. It might sound a bit hard, but as far as I’m concerned she can close her eyes. All she does is to sit in that chair, and nothing else. A year ago I wouldn’t have said that, but now I do.

Doctor L: Your mother is still here, but the real question is: what is her quality of life? On the other hand, we don’t have the impression that she’s suffering. And we’ll do everything we can to prevent that. We will continue to provide the best possible care for her. We offer her food and drink, and try to spoil her as much as possible. I’ll make a report of this discussion and record in the files that we have decided not to prolong the life of your mother unnecessarily, as they say in the medical terminology. If necessary, then we’ll discuss the matter again. Just because it’s written down, that doesn’t mean that we will do it whatever happens. We can discuss each new situation when it occurs.

Box 2: Fluids given in combination with medical treatment

Doctor R: I’m glad you could come so quickly. The situation has been getting a lot worse in the past few hours. Your mother is a diabetic, and the level of glucose in her blood fluctuates a lot. You know how much trouble we’ve had, since she was admitted three months ago, to regulate her glucose. But also, she’s not eating or drinking properly. She has lost four kilos in a very short time. So we need to do something about it.

(Mrs M’s daughter nods.)

Doctor R: A week ago she also got pneumonia, which we’ve given her antibiotics for. Since yesterday she’s been deteriorating. She’s dazed and is hardly eating anything at all. Today things have got worse again. She’s barely conscious, but she does react when you talk to her.

Mrs M’s daughter: With difficulty, doctor. I sit beside her bed and try to talk to her, but it’s almost impossible. Of course, she’s also almost blind and deaf, so that doesn’t make it any easier.

Doctor R: The situation is this. She hasn’t reacted well enough to the antibiotics, and therefore I want to prescribe another type of antibiotic. But that’s not all. Because of the fluctuating glucose levels, she’s dehydrated, and we will therefore have to give her extra fluids. Otherwise the antibiotics won’t work and it will be useless to prescribe them for her. Let’s put it this way: “If you say A, you’ve also got to say B.”

(Mrs M’s daughter nods again)

Doctor R: We give the fluid through small needles in the legs, and let it seep in. Sometimes she doesn’t want that.

(Mrs M’s daughter: She doesn’t want to be tube fed. She doesn’t want to have a tube."

Doctor R: Alright, then I’m going to arrange for her to be given the medicine and the fluids.

Doctor R: Does she ever talk to you about how she experiences life?

Mrs M’s daughter: She doesn’t want to die yet, she tells me. No, she doesn’t want that.

Doctor R: Alright, then I’m going to arrange for her to be given the medicine and the fluids.
Box 3: The amazing recovery of Mrs R

Mrs R, 81 years old, arrived at the nursing home in a bad state. After admission she deteriorated. She weighed less than 40 kg and was dehydrated. “In a dreadful state” was how the nursing staff described her. After discussing it with the family, doctor M decided to perform hypodermoclysis in both of Mrs R’s legs.

Doctor M: This caused tremendous opposition from the nursing staff. However could I think of artificially administering fluids to a woman in that state? I really had to do my best to explain that I also have my medical responsibilities and had to try it. I must honestly admit that I, too, didn’t have much hope. Well, that was three years ago, and if you see Mrs R now, would you ever imagine that she had been so far gone then? She’s made a wonderful recovery. She walks around the ward all day long tidying up and really is the sunshine in house. I use the example of Mrs R whenever the nurses protest about hypodermoclysis.

When acute illness was accompanied by dehydration, in most cases a decision was made to rehydrate the patient. If fluids were given artificially this happened only in combination with medical treatment (box 2). The argument was that “if you say A, you’ve also got to say B.”

In the case of brief acute illnesses or when the patient was in a poor condition or in end stage dementia, doctors were more reluctant to begin medical treatment, including the artificial administration of fluids and food. One doctor said that “patients are vulnerable—each period of treatment makes it more difficult to treat again. At a certain point it’s no longer beneficial.” In such situations the illness process was considered to be irreversible. If doctors anticipated this, they prepared the family by warning that more treatment wouldn’t help, which was recorded in the patient’s notes.

Unexpected fluctuation in the illness process: the dynamics

The decision to withhold the artificial administration of fluids and food was mainly dictated by the medical condition of the patient and the presence of acute illness. The course of the illness process, however, seemed difficult to predict. Some patients became suddenly ill and died, whereas those who were expected to die recovered unexpectedly, even after simple treatment (box 3). For individual patients various and even different decisions were made to withhold the artificial administration of fluids and food.

Decision processes

Living will and policy agreements

Patients were unable to make a choice for themselves about treatment, yet their wish was a factor in the decision making process. A written living will influenced the decision to withhold the artificial administration of fluids and food. Although euthanasia was not possible, the living will was considered to represent the patient’s wish not to prolong his or her life, which was respected. Written agreements were considered useful for dialogue with families, subsequent conversations, and locums. Unexpected fluctuations in the patient’s condition, however, influenced previous policy agreements; the doctors stated they mainly focused on the recent and current wellbeing (including prognosis) and quality of life of their patients.

Current verbal and non-verbal wishes

Some patients with early dementia clearly expressed their death wishes verbally, sometimes confirmed by the family (box 4). There also seemed to be non-verbal expressions of wishes; patients who gave the impression they were tired of life or even wanted to die—for example, by refusing food or drink (see bmj.com).

Although the ways in which a patient’s wishes were expressed were recorded by the doctors, important unexpected changes did occur. For instance, one patient who was thought to have a death wish, got out of bed after a few weeks. She said nothing about wanting to die, and gave the impression of enjoying life. When she developed pneumonia a year later, it was decided together with her son not to keep to the former policy agreement but to treat her with antibiotics and hypodermoclysis.

Control of staff and adaptation of family

The care of patients on trajectory 1 depended on nursing staff who rarely participated in the decision making process for withholding the artificial administration of fluids and food; they were informed and their opinions sought, but the doctors made the decisions. The doctors’ decisions were mostly influenced by their reaction to the patient’s condition and the patient’s family. The family had a considerable influence, formally as legal representatives; however, it was more their emotional response to the patient’s condition that was taken into consideration. The doctors explicitly considered the families’ feelings and preferences. If a patient did not give the impression of suffering, and a family needed more time, then treatment was provided.

Doctors and the families commonly had a long relationship: it was more difficult for locums and the doctors of patients who had recently arrived in the nursing home to make assessments (see bmj.com). The doctors considered the wishes of the families, but in the end they had control over treatment.

Discussion

Patients in nursing homes with dementia follow two illness trajectories that entail decisions about whether to
Informing participants of allocation to placebo at trial closure: postal survey

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Abstract

Objectives To assess whether and how investigators of placebo controlled randomised trials inform participants of their treatment allocation at trial closure and to assess barriers to feedback.

Design Postal survey with a semistructured questionnaire.

Participants All investigators who published a placebo controlled randomised trial in 2000 in five leading medical journals, and a random sample of 120 trials listed in the national research register database.

Main outcome measures Number of investigators who informed participants of their treatment allocation at trial closure, methods for delivering the information, and barriers to unmasking treatment.

Results 45% of investigators informed either all or most participants of their treatment allocation, and 55% did not inform any participant or only informed those who asked. The main reasons for not informing participants were that the investigators never considered this option (40%) or to avoid biasing results at study follow up (24%).

Conclusion Further research is required to examine sensitive ways to communicate treatment information to trial participants.

Introduction

In 1948 the Medical Research Council introduced a new experimental design to deal with therapeutic uncertainties. The randomised controlled trial aimed to ensure the absence of systematic differences between treatment and control groups. Placebos—surrogates for a control group receiving no treatment—were gradually adopted to act as dummy therapies to mimic the experimental treatment in appearance but not in substance or chemical structure.

Debate has focused on whether it is beneficial to withhold the artificial administration of fluids and food. Patients’ living wills seemed of limited importance, but policy agreements were useful in the decision making process and for dialogue with the family. In the end the medical condition of the patient, the wishes of the family, and the interpretations of the patients’ quality of life by their care providers were the most important criteria for withholding the artificial administration of fluids and food.

Doctors are constantly faced with uncertainties about what the patient wants. To reduce this uncertainty they try to create the broadest possible basis for the decision making process and its outcome, mainly by involving the family.

The two illness trajectories had different contexts and concerned different professionals. The second trajectory was characterised by medical decision making by doctors. The first trajectory, characterised by care from nursing staff, seemed the most vulnerable to continuity of care, communication problems, and scarcity of staff.

We identified repeated patterns of decision making. We assume our findings are generalisable because the patterns were observed in two nursing homes in different regions and by two researchers working independently. Further ethnographic research is needed to confirm the generalisability of our findings.

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