Culture and Medicine

When should physicians forgo curative treatment of pneumonia in patients with dementia?

Using a guideline for decision-making

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THE ETHICAL DILEMMA

The prognosis for a nursing-home patient with pneumonia is uncertain.[1] It is, therefore, hard to predict whether antibiotics and hydration—given to such patients with curative intent—turn out to be futile treatments. If patients die within a few days, they may well have suffered from the burden of receiving intravenous drugs and fluids. On the other hand, such treatments may actually reduce symptoms and, thus, suffering.

With demented patients, such treatment decisions are further complicated by ethical and legal issues. The patients' wishes are often unclear because they cannot competently evaluate the situation or communicate their wishes. The decision-making process is, therefore, complex and multifactorial.[2-4]

The *Western Journal of Medicine* recently published guidelines on "nonbeneficial or futile medical treatment," divided into those for patients with and those without decision-making capacity.[5] These were referred to as "conflict resolution guidelines." Although we acknowledge that roles and responsibilities in such guidelines need to be clear, additional dimensions need to be addressed.

With international support, as a Dutch research group, we developed a guideline aimed at supporting prudent decision-making for demented patients. This may prevent conflicts because it contributes to better decision-making. In this article, we briefly review the development and evaluation of our guideline. We then discuss how this guideline can be applied to clinical practice, an issue of interest to both clinicians and policymakers.

Summary points

- We have developed a guideline to help physicians to decide whether to forgo curative treatment of pneumonia in patients with dement a who live in nursing homes
- Decisions should take into account the medical aspects of each patient, the patient's autonomy and preferences, and if preferences are unclear, the patient's best interest
- The decision-making process may involve the family, nurses, and physicians, but the treating physician should ultimately decide
- Our guideline is useful mostly for complex cases, such as when patients' wishes are unclear or when their family and health professionals have opposing views

DEVELOPING OUR GUIDELINE

The guideline was developed for use by nursing-home physicians. It clarifies the steps that should be taken in the decision-making process when deciding whether to forgo curative treatment of pneumonia in demented nursing-home patients. When curative treatment is forgone, palliative treatment should be started.

Full details of how we developed our guideline have been published elsewhere.[6] Briefly, a "checklist of considerations" was drawn up, based on a literature review, discussion papers of Dutch medical associations, and consensus procedures with experienced nursing-home physicians and international experts in the fields of nursing-home medicine, ethics, and law.[7-10] This checklist was then piloted in clinical practice. Finally, a revised checklist was endorsed by all experts and authorized by the Dutch professional organization of nursing home physicians (NVVA) for use in a prospective study.

The checklist of considerations

The checklist of considerations, shown in part in figures 1 and 2, divides the decision-making process into 3 main areas: medical aspects, patients' autonomy and preferences, and patients' best interests.

Medical aspects

Little evidence exists to guide the medical aspects of the decision to treat curatively or palliatively. This aspect of the checklist addresses the expected outcome with curative treatment versus forgoing curative treatment (administering palliative care) and the burden of any curative treatment.

Autonomy and the best interests of the patient

The emphasis of the other 2 areas is on ethical and legal aspects. The checklist is based on well-known ethical principles that should guide physicians, including respect for autonomy, the duty to do good, doing no harm, and justice.[8]

Case 1

Mrs K, a widow with 1 daughter, was admitted to our nursing home with advanced vascular dementia. She had lived in a residential home but now required nursing care. She was disoriented, with severe cognitive impairment, aphasia, apraxia, and withdrawn behavior. She used a wheelchair and needed extensive help with her personal hygiene. During her stay, she developed depression. Despite medication, she was often restless, sad, or agitated. Her food and fluid intake was marginal despite dietician and nursing intervention. Advanced care planning had not taken place on admission.

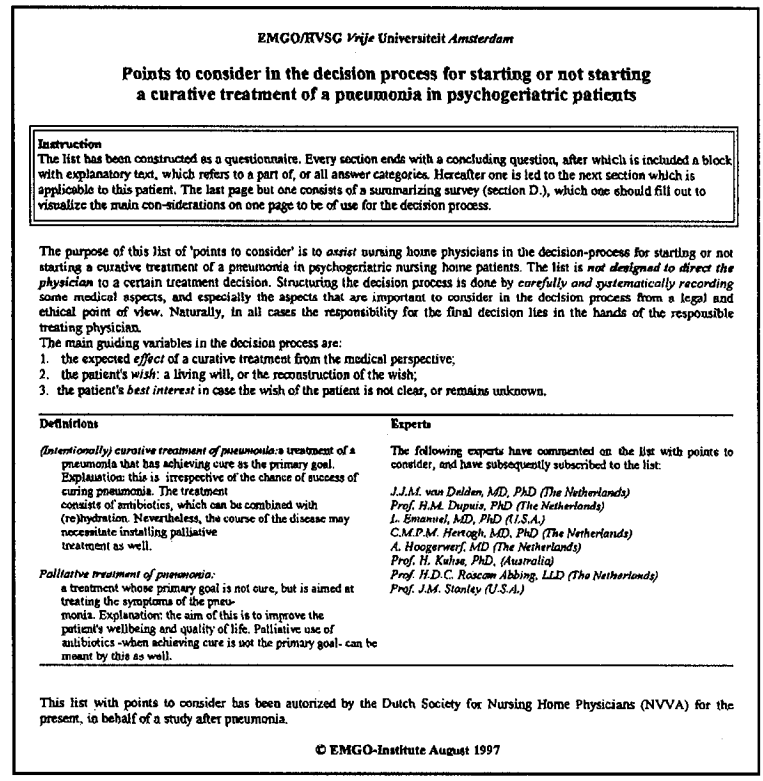
Six months after admission, she developed pneumonia and was at risk of dehydration. Based on the "checklist of considerations," we considered that a curative treatment would be effective only in part. We might have achieved cure but at the expense of an even lower level of physical and mental functioning because her health had been deteriorating during the past month. If cured, we expected her to suffer from a recurrent infection in the near future. Curative treatment seemed burdensome, given her restlessness—we would have to bind an intravenous line to her arm.

We contacted Mrs K's daughter, explaining the situation and the possible consequences of curative and noncurative treatment. Mrs K's wishes were not clear. She had not been capable of communicating this during her stay, she had no written will, and there was no other indication of what she would have wanted.

Considering what was in "the patient's best interest" (from the checklist), the daughter acknowledged that her mother's health was poor and that cure was unlikely. However, she judged that curative treatment should be given because she would not make a decision leading to her mother's death.

The last section of the checklist guided us through this difficult situation in which the physicians, nursing staff, and some of the family agreed on the treatment that was in the patient's best interests, but the daughter was unhappy about withholding a potentially curative treatment. Although the treating physician was responsible for deciding on Mrs K's treatment, we ideally wished to make a consensus decision. We therefore talked with Mrs K's daughter again. We explained that Mrs K's prognosis was poor, even with antibiotics. Her daughter agreed that she could not let her own feelings rule over what was in her mother's best interests. Mrs K received palliative treatment and died 4 days later.

The checklist was useful in this complex case, allowing us to consider the important issues in a systematic way. Although it did not help us in estimating her quality of life, or lack of pleasure in life, it did help us to look at the situation more objectively. It forced us to keep thinking and talking about the best decision.



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Points to consider in the decision process for starting or not starting a curative treatment of a pneumonia in psychogeriatric patients

Instruction
The list has been constructed as a questionnaire. Every section ends with a concluding question, after which is included a block with explanatory text, which refers to a part of, or all answer categories. Hereafter one is led to the next section which is applicable to this patient. The last page but one consists of a summarizing survey (section D.), which one should fill out to visualize the main con-siderations on one page to be of use for the decision process.

The purpose of this list of 'points to consider' is to *assist* nursing home physicians in the decision-process for starting or not starting a curative treatment of a pneumonia in psychogeriatric nursing home patients. The list is *not designed to direct the physician* to a certain treatment decision. Structuring the decision process is done by *carefully and systematically recording* some medical aspects, and especially the aspects that are important to consider in the decision process from a legal and ethical point of view. Naturally, in all cases the responsibility for the final decision lies in the hands of the responsible treating physician.
The main guiding variables in the decision process are:
1. the expected *effect* of a curative treatment from the medical perspective;
2. the patient's *wish*: a living will, or the reconstruction of the wish;
3. the patient's *best interest* in case the wish of the patient is not clear, or remains unknown.

Definitions

(Intentionally) curative treatment of pneumonia: a treatment of a pneumonia that has achieving cure as the primary goal. Explanation: this is irrespective of the chance of success of curing pneumonia. The treatment consists of antibiotics, which can be combined with (re)hydration. Nevertheless, the course of the disease may necessitate installing palliative treatment as well.

Palliative treatment of pneumonia: a treatment whose primary goal is not cure, but is aimed at treating the symptoms of the pneumonia. Explanation: the aim of this is to improve the patient's wellbeing and quality of life. Palliative use of antibiotics -when achieving cure is not the primary goal- can be meant by this as well.

Experts

The following experts have commented on the list with points to consider, and have subsequently subscribed to the list:

J.J.M. van Delden, MD, PhD (The Netherlands)
Prof. H.M. Dupuis, PhD (The Netherlands)
L. Emanuel, MD, PhD (U.S.A.)
C.M.P.M. Hertogh, MD, PhD (The Netherlands)
A. Hoogerwerf, MD (The Netherlands)
Prof. H. Kuhse, PhD, (Australia)
Prof. H.D.C. Roscam Abbing, LLD (The Netherlands)
Prof. J.M. Stanley (U.S.A.)

This list with points to consider has been autorized by the Dutch Society for Nursing Home Physicians (NVVA) for the present, in behalf of a study after pneumonia.

Figure 1 Slightly adapted version of the front page of the "checklist of considerations" (from the Institute for Research in Extramural Medicine [*Instituut voor Extramuraal Geneeskundig Onderzoek*; EMGO]/Department of General Practice, Nursing Home Medicine and Social Medicine [*Vakgroep Huisarts, Verpleeghuis-en Sociale Geneeskund*; HVSG] Vrije Universiteit Amsterdam)

In Dutch culture and law, patient autonomy is highly valued.[11] If patients are competent to make a decision, physicians must respect their wishes. If they lack the capacity to make a decision but have made a living will, then their wishes in the will should be respected. If no living will is available, patients' representatives—a curator or mentor, family, or friends—are asked. The professional carers should incorporate this information to try to determine patients' wishes.

If patients' wishes remain unclear, the last area of the checklist, discussing "the patient's best interest" can guide decisions. Both the representatives and the professional carers, including the responsible physician, are allowed to state what they think would be in the patient's best interests. Finally, the responsible physician decides on the treatment.

USING THE CHECKLIST IN CLINICAL PRACTICE

The checklist was introduced during an observational study on the clinical course of pneumonia in Dutch nurs-

D. Summarizing survey of the checklist of considerations

Copy the results of the preceding pages, as far as applicable.
Filling out part D is optional, however, part E should be filled out

A.1.6 Is an intentionally curative treatment indicated for this patient?

☐ Yes, indicated ☐ I don't know ☐ No, not indicated

A physician is not compelled to act if this is not medically effective. Moreover, a request to treat cannot be honored if the treatment at issue is not in agreement with the medical professional standards. According to -among others- CAL, starting a treatment is undesirable if it is considered to be not medically effective, irrespective the wishes and opinions of the patient and other persons involved.
There should be a dialogue, however, with the nursing staff and the patient's representative(s), explaining the undesirability of installing treatment that is not effective.

A.2.3 How physically and/or psychically burdensome would the total curative treatment -antibiotics and (re)hydration- be for the patient?

☐ Very burdensome ☐ Somewhat burdensome ☐ Not or little burdensome

When choosing the best treatment, beside the medical effectivity, the burden of treatment plays a part.

B.1.4 Is the patient sufficiently mentally competent, and if so, what treatment does the patient want?

☐ Insufficiently competent ☐ Sufficiently competent, wants curative treatment ☐ Sufficiently competent, wants palliative treatment

In this situation, merely the present wish of the patient applies and the rules for informed consent must be adhered to. Neither a written will, nor family or representative(s) do play a role in the decision process.

B.2.9 What is the purport of the written will?

☐ Unclear/absent ☐ Patient wants curative treatment ☐ Patient wants palliative treatment

In the WGBO a 'negative written will' has been given a legal status. A physician is compelled to follow the will when the patient does not wish a curative treatment, unless there are sufficient grounds (as mentioned in B.2.5 - B.2.8) not to do so.
As a rule, there should be a dialogue with the nursing staff and the patient's representative(s). The written will, however, is decisive.

B.3.9 What is the purport of the reconstruction of the patient's will according to the representative(s)?

☐ Absent / doubt / opposing opinions ☐ Intentionally curative treatment ☐ Palliative treatment

According to the WGBO, appointed as well as unappointed representatives have the authority to take decisions on the patient's behalf. The physician, however, retains his or her responsibility to test these decisions for medical effectiveness, and whether the representatives are actually reconstructing the wish of the patient (which has been tested in part B.3).

B.4.7 What is the purport of the reconstructed patient's wish according to the other involved professional carers?

☐ Doubt / opposing opinions ☐ Intentionally curative treatment ☐ Palliative treatment

The nursing staff and other (para)medics are not authorized to make decisions. The treating physician retains this responsibility.

C.5 Which treatment seems to be in the patient's best interest?

☐ Doubt / opposing opinions ☐ Intentionally curative treatment ☐ Palliative treatment

Finally, the physician bases his of her choice of the treatment on what is in the patient's best interest.

Figure 2 Part D of the decision-making questionnaire. WGBO = Dutch law on the medical treatment agreement (*Wet op de Geneeskundige Behandelings Overeenkomst*).

ing homes. For more than a year, use of the checklist was promoted but was not mandatory. The completed checklists were returned to the researchers.

The use of the checklist in these nursing homes has been evaluated (J T S, M E O, M W R, G W: "Decisions to Treat or Not to Treat Pneumonia in Demented Psychogeriatric Nursing Home Patients: Evaluation of a Guideline," unpublished data, date?). It was used in 50 of the 61 participating nursing homes and for about half of the patients (n = 228). Contrary to our expectations, the checklist was used as often in decisions about curative as about palliative treatment. It was used more often for less complex cases, such as when advanced care planning had already taken place. Nursing-home physicians did not use the checklist if the decision was already clear. Most physicians used it to confirm that they had the right decision in mind.

CASE HISTORIES

The 2 case histories were provided by 1 of us (T de G), who is a nursing-home physician and local coordinator of the Pneumonia Study in the Oostergouw Nursing Home. The cases are based on composites of 15 cases so as to protect the confidentiality of individual patients.

Case 2

Mrs B, a widow with 1 son, was admitted to the nursing home when she was 80 years old. She had lived alone, and it was becoming unsafe for her to cook meals. She had early Alzheimer's dementia and was disoriented, with diffuse memory disturbance and mild apraxia. She socialized well on the ward and seemed content. She was able to walk independently and needed minimal help with washing and dressing.

Her son visited her frequently. We discussed with him what should happen if his mother were to become unwell with an intercurrent illness. We decided that life-sustaining measures would be appropriate if they carried a high likelihood of cure.

When Mrs B developed symptoms and signs of bacterial pneumonia, we used the checklist of considerations in guiding us toward a decision. The first section—on medical aspects—was easy to fill out. Because her preexisting health was relatively good, we expected her to recover quickly from the pneumonia without any adverse effects of the treatment. Therefore, estimating her life expectancy, which was requested in this section, seemed pointless. We could not think of any burden of curative treatment because she was able to take oral antibiotics.

The next sections of the checklist concerned Mrs B's wishes. Her competence to understand her situation was moderately to severely impaired. We, therefore, did not want to discuss the progressive nature of the dementia with her or her limited life expectancy. Although she knew she was currently ill, Mrs B had no insight into the long-term consequences of any treatment and would not have given a reliable opinion. We told her that she had an "inflammation" of her lungs and that we would treat it. We contacted the family and nursing staff, who agreed that curative treatment was appropriate.

Mrs B was well within 4 days of antibiotic therapy and returned to her level of functioning before the pneumonia. In this case, because curative treatment carried little burden, the prognosis was good, and the patient's wishes had been discussed previously, the checklist provided little additional help in decision-making.

CONCLUSIONS

Development of the checklist involved translating *principles*, which were general guides, into *rules*, which were more specific to the decision to forgo antibiotic treatment in demented patients.[8] The next step will be to translate these rules to specific situations and apply the checklist in treatment decisions about individual patients. Because of the diversity of clinical contexts, this step may be even more challenging than the first. Forgoing curative treatment in demented patients suffering from pneumonia is a difficult and delicate decision.

An important ethical issue, as yet unresolved, is the application of the principle of autonomy to demented patients. The "protected milieu of autonomy" should be as inclusive as possible in demented patients.[12] Living wills are rarely available in these patients, at least in the Netherlands, making it more difficult to interpret patients' wishes. Patients with dementia may no longer be aware of their situation and the future, but they may enjoy other aspects of life. Insights from "ethics of care" may provide additional ways of dealing with this issue of former and current wishes.[13,14]

We hope that our checklist is used for supporting and guiding decisions, rather than being used in a purely directive way or only to confirm previous decisions. Physicians' responsibility does not end with the checklist. Instead, it is extended by the decision whether to use the checklist to optimize decision-making.

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