THE RISK SCORE FOR PATIENTS WITH PNEUMONIA AND DEMENTIA
EXPLANATION AND BACKGROUND

OBJECTIVE OF THE SCORE
The risk score (‘prognostic score’) is intended as an aid in the assessment of the risk of death within 14 days of the patient with pneumonia and dementia living in a nursing home or residential home (care home), if he or she were to be treated with antibiotics. The best prediction is based on a combination of using the risk score together with the physician’s own assessment (‘clinical judgment’).

USING THE SCORE
The score can be used as checklist to verify that you have included every relevant prognostic factor in your assessment (first table), as well as to gain insight into the risk of death (in that case you use the second table as well). The score is an aid and does not need to be used in all cases.

DECISION MAKING
Naturally a prognosis is only one element in your considerations regarding the treatment decision. In addition, the ‘points to consider in the decision-making process for curative or palliative treatment’ that are mentioned on the flip-side of the score play a role.

BACKGROUND
The background of the score is explained below using the six most frequently asked question about the score.

1. Why should I use the score?
The score can be useful in several ways, according to nursing home physicians and GPs who have used or evaluated the score:

In advance, when informing about the prognosis or making the treatment decision:
- to be better equipped to inform family and nurses about the prognosis;
- to increase due care in prudent decision making: checking whether all relevant factors regarding the prognosis have been taken into consideration (use as ‘checklist’);
- as an aid in the treatment decision in specific cases, for example when there is a difference of opinion between you and the family, or when you do not know the patient very well;

Afterwards:
- for better documentation of the prognosis and of how the prognosis was important in the decision making;
- as a learning instrument, to improve the personal prediction.
2. To use the score as an aid in the treatment decision I also want to know what the prognosis is without treatment with antibiotics. Can the score be used to establish that too?

The factors in the score’s first table are indeed important for the assessment of the prognosis in case of no treatment with antibiotics. However, the magnitude of the risk of death in case of no treatment is not represented by the percentage in the second table.

In the Netherlands, patients who are treated without antibiotics are much sicker than patients who are treated with antibiotics, but data from the USA - where the comparability of groups is much better - also show that the estimated risk of death within the first days or weeks is probably between 10% and 50% higher in patients who already have a relatively high score, and in patients with inadequate fluid intake. For patients with a low score and therefore a low risk of death, and in patients with adequate fluid intake, it is not clear whether antibiotics reduce the risk of death. In actual practice, however, almost all Dutch patients with a low risk receive treatment.

In practice the score can be useful when a symptomatic policy has been agreed, but the patient still seems in a relatively good condition. There is a substantial chance that life will be extended even without giving antibiotics, while antibiotics may possibly play a role in slightly reducing discomfort, and perhaps in cases like this also the duration of the discomfort.

3. How should I read the percentages?

The percentages apply to groups of patients, and provide an indication of the individual patient’s risk of death in the short term. Your clinical judgment is important to adjust that risk in special circumstances.

The literature recommends explaining the risk in the form of a frequency. For example: “out of every 10 patients like your mother, 4 die/survive the first 2 weeks”. Relatives usually do want to be informed about the prognosis – and regularly ask nurses about it – but they differ considerably in how they want to be informed. When asked some relatives expressed a preference for the version above, but we also found relatives who preferred hearing a percentage, or, often among elderly persons, a risk expressed in words (‘high’ or ‘low’). So the explanation needs to be tailored to each individual situation.

4. Why does the score not discriminate in higher risks of death?

This is in part because of characteristics of the population (total risk of death). In addition there were few patients who scored 23 points or more, which means the risk of death for this group cannot be determined with the same accuracy. It also means that you will probably encounter few patients with a score this high. The score is especially useful to determine who will probably not die in the short term when treated with antibiotics.
5. In which population was the score developed and validated?
The score was developed using the data of Dutch psychogeriatric residents of 61 nursing homes spread across the Netherlands, gathered in the late 1990s. Unlike other risk scores for pneumonia, this score was developed specifically for application in a vulnerable population with multi-morbidity. The score was validated in a population of nursing home residents with dementia in Missouri, USA. The antibiotics used were different, the population was not as sick as the Dutch population, and in all likelihood the pathogens were different also. Yet the risk score worked well there. This inspires confidence in its applicability not only in nursing homes but also in residential homes in the Netherlands.

The diagnosis was made by the physician, pneumonia being the probability diagnosis and generally no X-ray or laboratory diagnostics were involved.

The risk of death applies mainly to patients who are treated with oral antibiotics. When parenteral antibiotics are used, the risk of death in higher scores (starting at approx. 17) is lower than indicated in the table under the score, or in the figure on page 2.

6. How were the factors selected and why are, for example, comorbid illnesses and fever not included in the score?
The score was developed in such a way that the factors taken together give the best prediction. That is not to say that other factors do not have a predictive value, it just means that adding these factors to the existing score does not yield any surplus value. Comorbid disorders were not predictive of death within 2 weeks, but were predictive for death within a period of 3 months or longer. Other factors that were predictive are listed below, as are factors that were evaluated but found to be not strong enough, at least in combination with the other factors (for example: fever).

ADL dependence and male gender are generally very strong predictors for death in the next few months in patients with dementia with or without pneumonia.

<table>
<thead>
<tr>
<th>Independently predictive for the short term (1-2 weeks) but not included in the score</th>
<th>Only independently predictive in the longer term (1 month to many months)</th>
<th>Evaluated, but no independent predictor</th>
</tr>
</thead>
<tbody>
<tr>
<td>• increase in discomfort before diagnosis</td>
<td>• absence of coughing</td>
<td>• fever, falling, malaise, confusion, unrest, purulent sputum</td>
</tr>
<tr>
<td>• aspiration, swallowing problems</td>
<td>• dehydration</td>
<td>• incontinence, being bedridden</td>
</tr>
<tr>
<td>• physician’s assessment of how sick the patient is</td>
<td>• weight loss or eating little before diagnosis</td>
<td>• dependence dressing</td>
</tr>
<tr>
<td></td>
<td>• walking dependence</td>
<td>• CVA, depression, diabetes</td>
</tr>
<tr>
<td></td>
<td>• neoplasm, heart failure, Parkinson’s disease</td>
<td>• type and severity of dementia</td>
</tr>
</tbody>
</table>

* For pragmatic reasons: the measurement requires instruction (discomfort), there was no adequate equivalent available for validation or the definition was not clear cut, which can limit generalizability to other populations or settings.

Cut-off points were selected for particular factors to keep the score simple while retaining its predictive value. Different cut-off points were tested. The cut-off point for not drinking enough (less than 1.5 litres per day) may seem slightly high, but nursing home physicians often estimate sufficient intake at approximately 1.5 litres. The same is true of decubitus ulcers: every stage versus no decubitus ulcers.

Finally, the factors are not necessarily causally related to the outcome, i.e. cause death. Eating dependency in the diagnosis of pneumonia, for example, may be caused by the acute illness, but also by advanced dementia, or by eating problems caused by vascular diseases. This factor, as determined at the moment of the diagnosis of pneumonia, was a stronger predictor than eating dependency before the pneumonia.
References


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This explanation goes with a laminated version of the score and a form for nursing staff.