

# Development of a practice guideline for optimal symptom relief for patients with pneumonia and dementia in nursing homes using a Delphi study

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**Objective:** This study aimed to develop a practice guideline for a structured and consensus-based approach to relieve symptoms of pneumonia in patients with dementia in nursing homes.

**Methods:** A five-round Delphi study involving a panel consisting of 24 experts was conducted. An initial version of the practice guideline was developed with leading representatives of Dutch University Medical Centers with a department for elderly care medicine, based on existing guidelines for palliative care. The experts evaluated the initial version, after which we identified topics that reflected the main divergences. The experts rated their agreement with statements that addressed the main divergences on a 5-point Likert scale. Consensus was determined according to pre-defined criteria. The practice guideline was then revised according to the final decisions made by the project group and the representatives.

**Results:** The response rate for the expert panel was 67%. Main divergences included the applicability of guidelines for palliative care to patients with dementia and pneumonia in long-term care and the appropriateness of specific pharmacological treatment of dyspnea and coughing. Moderate consensus was reached for 80% of the statements. Major revisions included adding pharmacological treatment for coughing and recommending opioid rotation in the case of opioid-induced delirium. Two areas of divergent opinion remained: the usefulness of oxygen administration and treatment of rattling breath. The project group made the final decision in these areas.

**Conclusions:** We developed a mostly consensus-based practice guideline for patients with dementia and pneumonia and mapped controversial issues for future investigation. Copyright © 2014 John Wiley & Sons, Ltd.

**Key words:** nursing homes; dementia; pneumonia; Delphi study; quality improvement; practice guideline

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## Introduction

Pneumonia is a common event in nursing home residents with dementia. The illness may be associated with severe discomfort, irrespective of whether antibiotics are used (van der Steen *et al.*, 2002a). Treatment of pneumonia in dementia involves specific challenges, because patients are not always able to verbalize symptoms. Further, symptoms such as behavioral changes may not be specific for pneumonia. The dementia increases mortality risk (van der Steen *et al.*, 2002b), and palliative treatment is an option.

Evidence on effectiveness of comfort-enhancing treatments for pneumonia, such as when to use opioids or oxygen, is sparse. This applies to older people in general but especially so to patients with dementia. With little or no specific evidence available, we must rely on existing guidelines designed for other patient groups such as palliative care guidelines in general or on consensus among experts on treatment specifically in this population (Arcand *et al.*, 2007; Gove *et al.*, 2010).

Treatment approaches may vary substantially between nations, because of a lack of uniformity in nursing home settings and organization of care (van der Steen *et al.*, 2004). In Dutch nursing homes, elderly care physicians are on the staff and are responsible for treatment decisions and medical care (Hoek *et al.*, 2001; Hoek *et al.*, 2003; Koopmans *et al.*, 2010).

In this paper, we report on the stepwise development of a practice guideline for optimal symptom relief and comfort specifically for patients with pneumonia and dementia. Antibiotics may be used for the treatment of pneumonia, depending on treatment goals and family preferences. As it is unclear whether antibiotics help to relieve the symptoms of pneumonia, in addition to other treatment to relieve symptoms, they are not addressed in the practice guideline or in this paper.

We describe the process of guideline development based on evidence where available and consensus using a Delphi method with a multi-professional panel. In addition, we cover important conceptual issues encountered during the process, such as to what extent existing guidelines for palliative care are useful for patients with pneumonia and dementia, how to provide guidance when specific evidence or international consensus is lacking, and how to best target a local situation.

## Methods

We chose a Delphi procedure to reach consensus, because it enables interaction between a large group of (inter)national experts. In addition, experts'

identities are kept confidential, avoiding dominance of one expert over the other (Adler and Ziglio, 1996; Campbell *et al.*, 2003). The Delphi procedure comprised five rounds of which three were partly (Round 2) or fully (Rounds 3 and 4) quantitative and involved an expert panel (Table 1). The project group selected 24 experts with expertise in dementia, palliative care, pharmacy, infectious diseases, palliative care, hospice care, elderly care medicine, general practice, nursing, family medicine, and geriatrics from their scientific networks based on previous or ongoing (inter)national collaborations (Table 1).

### Initial guideline development: Round 1

The initial version of the practice guideline was based on general evidence and consensus-based palliative care guidelines developed by the comprehensive cancer center the Netherlands (IKNL) (de Graeff *et al.*, 2010), on clinical experience, and on available educational material recommended by the guideline consultants (Table 1). First, we reviewed the guidelines for dyspnea, nausea and vomiting, coughing, care in the terminal phase, fever, dehydration and fluid administration, pain, delirium, and fear/anxiety (de Graeff *et al.*, 2010). To examine whether recommendations in the guidelines did also apply to patients with dementia and to ensure we included all existing literature, we checked the reference lists of the guidelines and initiated extra literature searches in PubMed, Google Scholar, and reference lists of relevant articles for all separate symptoms of pneumonia that are addressed in the practice guideline. However, these searches generally confirmed a lack of evidence specific to patients with dementia and pneumonia.

Each recommendation from the palliative care guidelines was considered separately, and we considered whether (a) the recommendation was relevant and applicable to patients with dementia, (b) medications and doses recommended were suitable for older people, (c) medications and administration routes were available in (Dutch) nursing homes, for example, parenteral administration is uncommon, (d) medications were applicable for a short-term intermittent disease, for example, slow-release opioids are not, and (e) treatments recommended were not too burdensome for patients with dementia. Thereafter, the guideline consultants reviewed an initial version of the practice guideline (Table 1). Their feedback was considered in a face-to-face discussion among the project group and leading representatives of Dutch University Medical Centers with a department for

Table 1 Delphi rounds

Round	Method	Goal	Contributors (numbers)	Expertise
Initial guideline development	1 Qualitative	Development initial version practice guideline, based on evidence, clinical experience, and consultant advice	Project group (5)  Representatives (3)  Guideline consultants (4)	Pharmacy, epidemiology, clinimetrics, ethics, elderly care medicine, <sup>a</sup> including leading representatives of two of five Dutch University Medical Centers with a department for elderly care medicine Leading representatives of all Dutch University Medical Centers with a department for elderly care medicine Trainers in educational programs at post-doctoral level, in elderly care medicine, palliative care, and psychogeriatrics
International expert rounds	2 Qualitative and quantitative	Defining divergent topics	National (15) and international (9) experts including all project consultants (3)  Response: 22 of 24 invited experts (92%)	Palliative care, hospice care, elderly care medicine, general practice, infectious diseases, nursing, pharmacy, family medicine, geriatrics
	3 Experts evaluate the guideline and provide comments in writing Quantitative	Quantify expert opinions on divergent topics	National (10) and international (8) experts  Response: 18 of 22 invited (75% of initial invitees)	Palliative care, hospice care, elderly care medicine, general practice, nursing, pharmacy, family medicine, geriatrics
	4 Experts rate their agreement with statements representing nine topics on which opinions diverged Quantitative	Revision, feedback and reevaluation to increase consensus	National (9) and international (7) experts  Response: 16 of 18 invited (67% of initial invitees)	Palliative care, hospice care, elderly care medicine, general practice, nursing, family medicine, geriatrics
Final discussion	5 Experts rerate statements about seven remaining topics on which opinions diverged Qualitative Final decisions about all topics and statements after group discussion	Finalize product based on evidence and consensus	Project group (5) Representatives (3) Project consultants (3)	Same expertise as in Round 1 Same expertise as in Round 1 Infectious diseases, family and community medicine

<sup>a</sup>Dutch medical specialty emerged from nursing home medicine and community geriatric medicine (Hoek *et al.*, 2001; Hoek *et al.*, 2003; Koopmans *et al.*, 2010).

elderly care medicine. These representatives represented the end users, which were elderly physicians who were to use the guideline in practice. All input of the guideline consultants was therefore considered from the viewpoint of elderly physicians in nursing homes. This revealed that some recommendations were too elaborate and others lacked detail. For example, some recommendations were regarded generally known in this population such as the diagnosis and definition of some symptoms and the treatment of unwanted side effects of specific medications. Furthermore, on the basis of suggestions of the guideline consultants, the representatives decided about the ultimate structure and sequence of the recommendations in the guideline.

#### International expert rounds: Rounds 2–4

In Round 2, the 24 selected experts (Table 1) who joined the Delphi study were asked to critically evaluate the parts of the practice guideline that matched their expertise, to provide feedback, and if available, evidence to support their feedback. The feedback was summarized by topic to provide an overview of topics that were mentioned by at least three experts. Nine topics showed major divergences, which were addressed with 43 statements (40 for international experts and three statements were only relevant for the Dutch situation; Supporting information).

For Round 3, we sent the experts a PDF form containing the statements. To avoid response set bias, we formulated some of the statements so that the expected response would be negative. The experts were asked to rate their level of agreement or disagreement with the statements using a 5-point Likert scale (Table 2) (Hanlon *et al.*, 2009; Junger *et al.*, 2012) and were invited to provide feedback, comments, and evidence to substantiate their answers. The median of all answers, as well as the interquartile range (IQR), was computed. The criteria for consensus were determined *a priori* (Table 3). We decided to accept a moderate level of consensus because the statements reflected divergences, and therefore, discrepancies were expected. When statements met more stringent

Table 2 Assessment of agreement

Level of agreement on 5-point Likert scale
1 = strongly disagree
2 = moderately disagree
3 = neither agree nor disagree
4 = moderately agree
5 = strongly agree
6 = do not know

Table 3 Criteria for consensus

Criteria for consensus	Median	IQR
Moderate consensus on agreement with statement	4 or 5	≤2
Moderate consensus on disagreement with a statement	1 or 2	≤2
Strong consensus on agreement with statement	4 or 5	≤1
Strong consensus on disagreement with a statement	1 or 2	≤1
No consensus	1 or 2 or 4 or 5 3	>2 —

criteria (IQR of ≤1 instead of ≤2; Junger *et al.*, 2012), this was regarded as *strong* consensus (Table 3).

In Round 4, only the statements that were classified as no consensus were sent back to the experts, together with median scores from all raters, their individual scores, and all feedback of other experts. Taking into account the prior scores and feedback, the experts were asked to again rate their level of agreement on the 5-point Likert scale. The experts also indicated whether they felt they could “live with it” if we adopted the statement as is (Haggerty *et al.*, 2007). Finally, they were asked to answer two general questions about the practice guideline: whether in general they felt the practice guideline represented practice that is different from usual practice in elderly care medicine and whether complying with the practice guideline would result in a significant proportion of the patients with pneumonia and dementia being more comfortable compared with usual practice. Scores were classified similarly to the approach in Round 3. All statistical analyses were performed using SPSS version 20.0 for Windows (SPSS Inc, Chicago, IL, USA).

#### Final discussion: Round 5

All remaining statements and feedback of the experts were discussed in a meeting with the project group and the representatives. For each statement, the options were to stay with the original recommendation or to adapt the practice guideline. Adaptations were classified as either *major* revisions, which refer to reversion of advice, dose adaptations, and major textual adjustments, or *minor* revisions, which were limited to clarifying advice or minor textual adjustments.

## Results

#### Initial guideline development: Round 1

The structure of the practice guideline remained largely unchanged throughout the Delphi rounds.

The practice guideline consists of an introduction (I), a checklist of symptoms (II), and the core guideline (III–IV). The introduction provides instructions for use and explanation about care goals. The checklist lists possible symptoms of pneumonia to assess the patient's overall condition and recommends observational instruments to monitor pain and dyspnea, which had been thoroughly validated locally (the Dutch translation) or also internationally (Warden *et al.*, 2003; Zwakhalen *et al.*, 2006; Zwakhalen *et al.*, 2007; Fuchs-Lacelle *et al.*, 2008; van Herk and van Dijk, 2009; Campbell *et al.*, 2010). The core guideline is structured according to five symptoms that are closely related to pneumonia, such as dyspnea and fever, and four indirect symptoms, such as pain and dehydration.

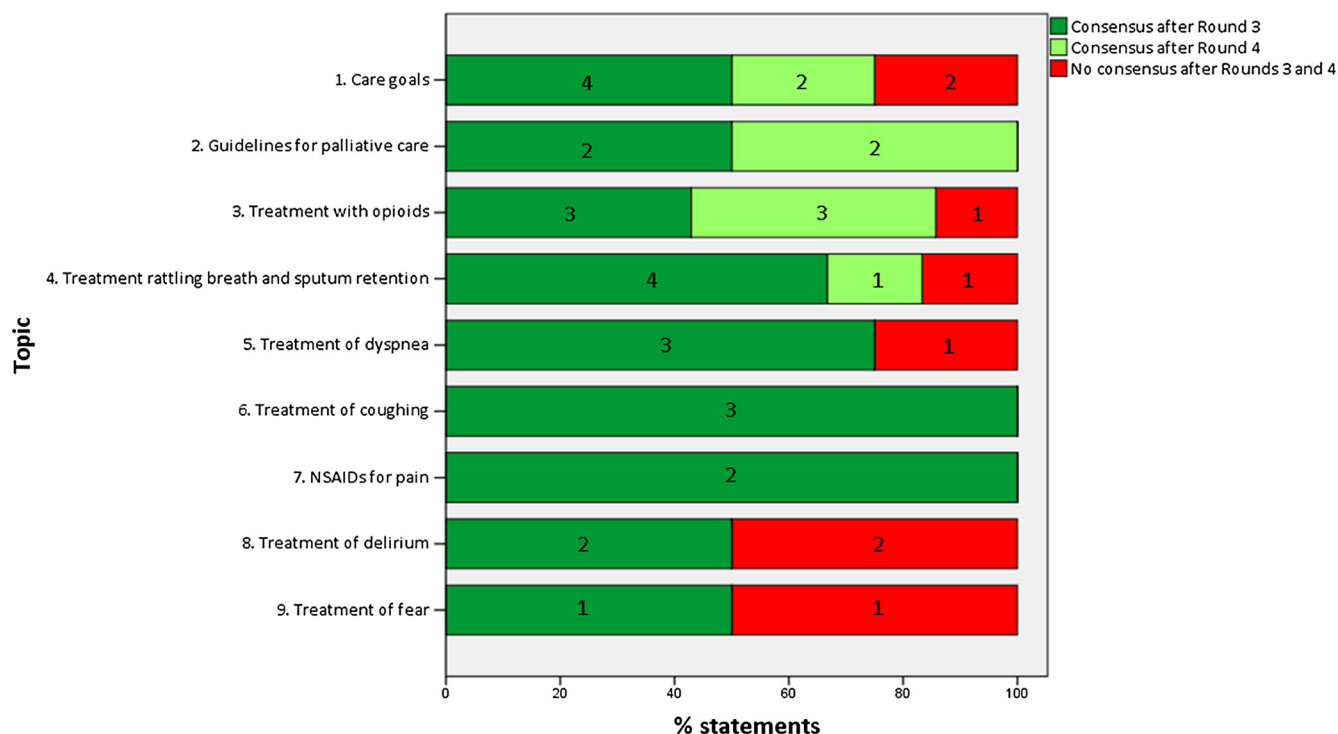
#### International expert rounds: Rounds 2–4

Response rates for the second, third and fourth Delphi rounds were 92% (22/24), 75% (18/24), and 67% (16/24), respectively. Reasons for non-response were holidays (2), lack of time (2), unease with the explanation of care goals (1), and unknown (3). Overall, 68% (15/22) of all experts were men, and 59% (13/22) were Dutch. Other nationalities included American (3),

Canadian (1), British (1), Italian (1), German (1), Swiss (1), and Czech (1).

The experts agreed that, overall, the practice guideline differs from usual practice (median = 4, IQR = 1; Supporting information) and that complying with the practice guideline would result in a significant proportion of the target patients being more comfortable (median = 4, IQR = 0; Supporting information). Figure 1 lists the nine main topics on which opinions diverged and shows the proportion of statements that did or did not reach consensus in Rounds 3 and 4 for each of the topics.

One of the topics on which opinions diverged most from the feedback in Round 2 was the application of existing guidelines for palliative care (IKNL, de Graeff *et al.*, 2010). Experts in palliative care claimed that the palliative care guidelines can and should be applied without change for the treatment of patients with pneumonia and dementia. In contrast, elderly care physicians generally felt that these guidelines provide useful input but that application depends on the dementia stage, on policy agreements, and on medical–ethical considerations. Other topics on which opinions diverged were whether or not to recommend a different treatment for two types of comfort care goals used nationally (Verenso, 1997), treatment of dyspnea,



**Figure 1** Proportion of statements per topic that did or did not reach consensus after Round 3 or 4. Numbers refer to numbers of statements.



coughing, delirium and fear, the role of opioids in pneumonia treatment, and specific therapies such as NSAIDs for pain, and anticholinergics for rattling breath.

In Round 3, moderate agreement was achieved for over half (60%, 24/40) of the statements (Supporting information). For two of the nine topics—treatment of coughing and NSAIDs for pain—agreement was reached for all statements after this first quantitative evaluation (Round 3). For the treatment of coughing, experts strongly agreed with the statements. In the initial version of the practice guideline, pharmacological treatment of coughing was not recommended, but opinions diverged about this topic in the feedback from Round 2. The results of Round 3 showed that most experts agreed that treatment with opioids must be assessed individually and should certainly be applied when the coughing is burdensome for the patient. The experts agreed that using NSAIDs for pain has no additional benefit over acetaminophen. Of the remaining seven topics, at least one of the corresponding statements did not reach consensus. Overall, 40% (16/40) of statements were reported back to the experts in Round 4.

In Round 4, consensus was reached for all statements about guidelines for palliative care. Experts revised their agreement with the statements about the applicability of guidelines for palliative care in response to the other experts' feedback. Ultimately, it was accepted that we must assume that guidelines for palliative care are applicable and also that it is acceptable to adapt the guidelines to make them more specific for patients with pneumonia and dementia in nursing homes. Likewise, eight additional statements reached agreement, resulting in consensus about most (80%, 32/40) of the statements.

Final discussion: Round 5

In a final discussion of the previous rounds, the project group and representatives decided about major and minor adaptations considering each statement (Table 4, Figure 2). For eight statements that did not reach consensus, the expert opinions were mostly not very pronounced, and applying minor adaptations such as a clarification of the recommendation sufficed (Figure 2, Table 4). One of the minor revisions was about administration of oxygen to relieve dyspnea. Because the experts' opinions differed and evidence is sparse (Abernethy *et al.*, 2010; Campbell *et al.*, 2012), we included the need for oxygen administration to be assessed individually.

We decided that for 19 of the 32 statements that reached consensus, the recommendation in the initial

version was adequate. For three statements about the treatment of rattling breath with anticholinergics, we chose not to adopt the opinion of most experts. A majority of the project group and representatives was against treatment, because of adverse effects and lack of evidence to support the efficacy (Wee *et al.*, 2008; Heisler *et al.*, 2013). For this topic, we weighed the views of Dutch contributors higher than feedback of international experts, as the practice guideline was to be implemented in the Netherlands first. For this, and other recommendations in the practice guideline that were based on majority decisions of the representatives rather than on consensus among the experts, we highlighted this recommendation with the letter (M).

Thirteen of the 32 statements that reached consensus led to major or minor revisions of the practice guideline in view of the feedback (Figure 2). For example, we added the treatment of coughing with opioids only when the coughing is burdensome for the patient. Further, we de-emphasized the distinction between different comfort care goals (Table 4).

For two remaining statements that reached consensus, about the dosing of haloperidol for delirium and about the non-pharmacological treatment of fear/anxiety, it was decided that no adaptations were necessary. This decision was underlined by the results of the question whether the experts could "live with it", which was answered positively for those two statements by 87% and 93% (31–93% for all statements in Round 4) of the experts, respectively.

## Discussion

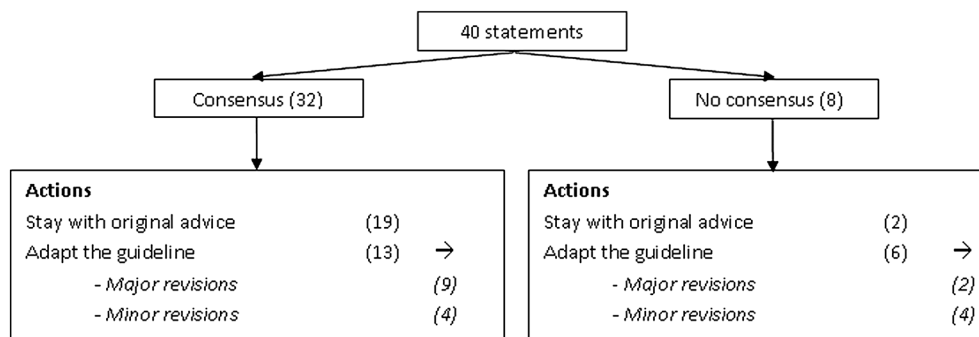
This paper describes the development of a practice guideline for a comfort-enhancing treatment of patients with dementia suffering from pneumonia and the conceptual issues we encountered during development. Despite a sparse evidence base and initial divergences in expert opinions, at the end of the process, the experts expected the use of the practice guideline to improve comfort.

Initially, only one qualitative round was planned in which experts were asked to provide specific feedback on the practice guideline. The resulting feedback made clear that lack of evidence and different clinical views led to much more variation in expert opinions than anticipated, both among and between (inter)national experts. Some of the discrepancies originated from different views among the several specialties represented. For most topics, existing guidelines for palliative care needed to be adapted, including for the treatment of dyspnea, coughing, delirium, and

Table 4 Revisions in response to the Delphi study panelists' evaluations

Statements	Subject	Initial version	Final version
Major revisions Care goals (1.1, 1.3)	Distinction between care goals	The distinction between care goals was integrated in all parts of the guideline	Only for symptoms where the care goals are relevant does the guideline distinguish between the care goals. The distinction itself is reduced to weighing of two aspects: (1) life expectancy and (2) undesirability of life extension
Treatment with opioids (3.3)	Delirium as side effect of opioids	No recommendations	When opioids are the suspected cause of the delirium, it is recommended to lower the dose of the opioids, to change route of administration, or to consider opioid rotation
Treatment with opioids (3.6), and treatment of delirium (8.2)	Care goals versus short life expectancy for haloperidol and laxatives	Treatment of a delirium with haloperidol and supplying a laxative with opioid treatment depend on the care goal of the patient	Treatment of a delirium with haloperidol and supplying a laxative with opioid treatment may be withheld when life expectancy is very short (max 1–2 days)
Treatment of dyspnea (5.2)	Measurement of oxygen saturation	Oxygen saturation may be measured to assess if there is hypoxemia	Measuring the oxygen saturation is not recommended because hypoxemia often does not explain the dyspnea
Treatment of dyspnea (5.4)	Pharmacological treatment of dyspnea	Dyspnea should only be treated with opioids and not with additional agents such as corticosteroids and bronchodilators	Treatment of dyspnea with corticosteroids and bronchodilators is recommended in addition to opioids in the case of obstruction or exacerbations of chronic obstructive pulmonary disease
Treatment of coughing (6.1–6.3)	Treatment coughing	Pharmacological treatment of coughing is not recommended	Treatment of coughing with opioids is recommended when the coughing is burdensome for the patient
Treatment of delirium (8.1)	Non-pharmacological treatment delirium	Ensuring a safe environment and limiting stimuli may increase comfort	The non-pharmacological treatment is of major importance in controlling delirium. Family may have a significant role in this. The advice is supplemented with examples
Minor revisions Treatment of rattling breath and sputum retention (4.1–4.4)	Treatment of rattling breath with anticholinergics	Anticholinergic agents are not recommended for the treatment of rattling breath	The effectiveness of pharmacological treatment with anticholinergics to relieve sputum retention or rattling breath in patients with dementia and pneumonia has been insufficiently studied
Treatment with opioids (3.7), and treatment of delirium (8.3)	Prognosis versus short life expectancy for haloperidol and laxatives	Treatment of a delirium with haloperidol and supplying a laxative with opioid treatment depend on the prognosis of the patient	Treatment of a delirium with haloperidol and supplying a laxative with opioid treatment may be withheld when life expectancy is very short (max 1–2 days)
Treatment of dyspnea (5.1, 5.3)	Oxygen administration	Oxygen may be administered when needed	The decision to administer oxygen depends on the individual situation and burden for the patient

Numbers refer to numbers of statements in the Supporting information.



**Figure 2** Major and minor revisions for statements that did or did not reach consensus in the last quantitative Delphi round (Round 4). The revisions correspond to rating of statements that resulted in revisions of the guideline referring to the first round that involved an expert panel (Round 2). Numbers refer to numbers of statements.

fear. This was also true for the role of opioids in the treatment of pneumonia and for specific therapies such as NSAIDs for pain and anticholinergics for rattling breath. We therefore performed additional quantitative Delphi rounds.

#### Palliative care guidelines

The initial version of the practice guideline was based on available guidelines for palliative care, which we adapted to make them more applicable to our target population. On the basis of the risk of dying, pneumonia in a patient with dementia can often be regarded as a terminal diagnosis for which palliative care applies (Morrison and Siu, 2000). Although no evidence demonstrates that these guidelines are not applicable in this specific population, in practice, patients with dementia frequently require a different approach. For example, typical symptoms of infections are often absent, and other symptoms may be more pronounced complicating the diagnosis. Because patients with dementia are often unable to express their concerns, their wishes about treatments to be provided are often unknown. Furthermore, the end-of-life trajectory of patients with dementia is slower and prolonged for many years compared with a relatively rapid functional decline in cancer. And last, dementia-related intake problems may require complex decisions about (discontinuation of) artificial hydration and feeding tubes (Pasman *et al.*, 2005; van der Steen *et al.*, 2013; van der Steen *et al.*, 2014). Moreover, the nursing home setting has its limitations. For example, opioids other than morphine and fentanyl are not conventional in the Dutch nursing home setting, and therefore, offering a long list of alternatives to morphine is not relevant. Moreover, pneumonia is an acute intercurrent disease with specific symptoms that cannot always be compared with symptoms due to diseases such as cancer or

chronic obstructive pulmonary disease for which the guidelines were developed originally. This implies, for example, a focus on short-acting instead of slow-release opioids. Ultimately, the experts agreed that the guidelines for palliative care are generally applicable but that it is acceptable to adapt them.

For the topic about treatment of rattling breath, the quantitative Delphi rounds could not solve discrepancy between the experts—who generally favored treatment with anticholinergics—and the project group, where a majority was against the administration of anticholinergic agents. Anticholinergics such as scopolamine and atropine are frequently used to attenuate rattling breath or “death rattle”.

Employing anticholinergics is generally based on pathophysiological considerations, but there is no clinical evidence of effectiveness (Wee and Hillier, 2008; Gerretsen and Pollock, 2011; Heisler *et al.*, 2013). Rattling breath might not add to the patient’s pain or discomfort but may be experienced as stressful by family and nursing staff (Wee *et al.*, 2006; Wee *et al.*, 2008). As palliative care includes care for relatives, the experts would administer anticholinergics only to comfort family. Nevertheless, we put the patients’ interest first and preferred to comfort relatives by education about symptoms. In this regard, a cross-national study examining decision making in pneumonia and dementia (Helton *et al.*, 2006) found that Dutch physicians focus more on their responsibility for the patient regardless of family opinions, whereas US physicians are influenced more strongly by family wishes.

#### Strengths and limitations

The strengths of this study were input from a multidisciplinary expert panel and the application of both qualitative and quantitative methods to systematically map opinions and divergences in the treatment of



pneumonia in patients with dementia. The Delphi procedure was a valuable tool to transparently quantify the (inter)national views on enhancing comfort, especially for the topics and treatments that lack evidence.

Some limitations should be acknowledged. First, our goal was to develop a practice guideline to enhance comfort about which practitioners in the Netherlands and elsewhere would on the least say they “can live with” (Haggerty *et al.*, 2007). Taking this into account, the criteria for consensus (median = 1, 2, 4, or 5 and IQR ≤ 2) we set up were not conservative but suitable to facilitate the process of achieving a reasonable amount of consensus on a relatively large number of divergent issues.

Although we aimed at including experts of all relevant fields, we weighted expertise to include generalists specialized in the topics through research or practice. As a result, we did not focus on specific expertise in respiratory disease and physical therapy. This, along with the nationality of experts, potentially impacted the content of divergent topics addressed in the statements and the statements that did or did not reach consensus.

For some topics, the opinions varied too much within the expert panel, or a discrepancy remained between the experts and the project group. In a few cases, we prioritized majority decisions in the project group over the opinion of most experts—even when this opinion represented the international consensus—and highlighted this in the practice guideline. These decisions deviating from consensus sometimes involved considerations that had an ethical rather than a medical or technical nature. As we weighted the views of Dutch experts and project group members highest, the present practice guideline is only definitely suitable for use in Dutch nursing homes. Certain recommendations should be reevaluated in other countries because when literature and consensus were lacking, we prioritized the situation in the Netherlands. For example, we discourage the use of anticholinergic drugs for rattling breath or sputum retention, which is not internationally accepted. This and other areas of deviation from the international consensus are highlighted in the practice guideline and remain important areas for international dialogue and research on optimum care at the end of life.

## Implications

We developed a practice guideline for optimal symptom relief for patients with pneumonia and dementia,

which is ready to be tested in clinical practice in the Netherlands. The practice guideline will be implemented in about 20 nursing homes in which physicians use it in addition to their own clinical judgments and is tested for effectiveness to decrease discomfort. Further implementation studies may highlight areas that need adaptation to local settings.

## Conflict of interest

None declared.

### Key points

- Pneumonia in patients with dementia may cause severe discomfort, and evidence on effectiveness of comfort-enhancing treatments is sparse.
- To develop a practice guideline to relieve symptoms, we used a Delphi procedure based on both evidence and consensus.
- We departed from general guidelines for palliative care, and adapted for dementia and the Dutch nursing home setting.
- A number of divergences remained including experts differing on usefulness of oxygen and treatment of rattling breath.
- The practice guideline may need adaptation to local settings.

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