

End-of-life treatment decisions in nursing home residents dying with dementia in the Netherlands

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Objective: The objective was to describe end-of-life treatment decisions for patients dying with dementia in various stages of dementia in long-term care facilities in the Netherlands with elderly care physicians responsible for treatment and care.

Methods: We present data collected in the nationally representative Dutch End of Life in Dementia study (2007–2011). Within 2 weeks after death, 103 physicians completed questionnaires about the last phase of life in 330 residents with dementia who resided in 1 of 34 participating long-term care facilities. We used descriptive statistics.

Results: Advance directives were rare (4.9%). A minority was hospitalized (8.0%) in the last month (mainly for fractures) or received antibiotics (24.2%) in the last week (mainly for pneumonia). Four residents received tube feeding or rehydration therapy in the last week. In almost half of the residents (42.3%), decisions were made not to start potentially life-prolonging treatment such as hospital transfer and artificial nutrition and hydration. In more than half of the residents (53.7%), decisions were made to withdraw potentially life-prolonging treatment such as artificial nutrition and hydration and medication. Antibiotics were more frequently prescribed for residents with less advanced dementia, but otherwise there were no differences in treatment decisions between residents with advanced and less advanced dementia.

Conclusions: Physicians often withhold potentially burdensome life-prolonging treatment in nursing home residents in all stages of dementia in the Netherlands. This suggests that the physicians feel that a palliative care approach is appropriate at the end of life in dementia in long-term care. Copyright © 2016 John Wiley & Sons, Ltd.

Key words: Dementia; end of life; treatment decisions; palliative care; long-term care

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Introduction

In our greying societies, many older people, up to one in three, will die with or from dementia (Weuve *et al.* 2014). Because of the loss of cognitive abilities, most are unable to make treatment decisions at the end of life. In many countries, more than half of people with dementia die in long-term care settings (Houttekier *et al.* 2010).

Mitchell *et al.* (2009) reported in 2009 that nursing home residents with advanced dementia frequently underwent burdensome interventions in nursing homes in the USA and recommended that residents with advanced dementia need a palliative care approach. Although a palliative care approach is more generally accepted in later stages of dementia, a palliative care approach may also be justified earlier (van der Steen *et al.* 2014a).

In the 90s, a palliative approach was introduced to the Dutch nursing home setting (Hertogh 2006; Hertogh & Ribbe 1996), and nowadays, this approach is generally accepted in the Netherlands for residents admitted because of dementia (Hendriks *et al.* 2014; Bouwstra *et al.* 2015; Hertogh & Ribbe 1996). In Dutch nursing homes, certified elderly care physicians are on the staff, usually know the patient and family well, and have a strong and often decisive influence on decision making (Helton *et al.* 2006; Helton *et al.* 2011; Koopmans *et al.* 2010). Besides providing symptom management, elderly care physicians may facilitate discussions on advance care planning and develop care plans (Hendriks *et al.* 2014; Hertogh 2006).

The majority of residents with dementia in Dutch nursing homes have a palliative care goal (Hendriks *et al.* 2014; Bouwstra *et al.* 2015; van Soest-Poortvliet *et al.* 2014). Such a goal may frame decisions to withhold potentially burdensome life-prolonging treatment such as resuscitation, hospitalization, drugs and artificial nutrition and hydration. However, no nationally representative data about treatment decisions at the end of life of nursing home residents with various stages of dementia have been available so far. In this article, we describe end-of-life treatment decisions in nursing home residents dying in various stages of dementia in Dutch long-term care facilities and cared for by elderly care physicians.

Methods

We analysed data collected in the Dutch End of Life in Dementia study (DEOLD: assessments 2007–2010;

monitoring of survival up to 2011) (van der Steen *et al.* 2014b). The primary aims of DEOLD-study were to describe quality of dying and end-of-life care and overall quality of care provided as evaluated by families and assess associated factors. In the DEOLD study, 34 long-term care facilities participated, and the facilities belonged to a total of 19 care organizations (sharing physician teams). The study was representative for the Netherlands in terms of geographic distribution (van der Steen *et al.* 2014b). One of two observational designs was used per care organization: a prospective recruitment of residents (upon admission, with follow-up until death or until the end of data collection) or a retrospective (after death) recruitment.

Residents with a dementia diagnosis admitted to a psychogeriatric ward (almost all dementia) were enrolled. Characteristics of the residents have been published elsewhere; most residents (66.7%) were female, mean age at death was 85.2 years (Hendriks *et al.* 2016b), and most residents (91.1%) had a palliative care goal at the day of death (van Soest-Poortvliet *et al.* 2014). The study protocol was approved by the Medical Ethics Review Committee of the VU University Medical Center Amsterdam, and written informed consent was obtained from the families.

Data collection

Within 2 weeks after death, 103 elderly care physicians completed questionnaires about 330 of 339 residents with dementia who died within the period of data collection (resident assessments up to summer 2010) (Hendriks *et al.* 2016a; van der Steen *et al.* 2014b). In the prospective design, 218 residents died during the assessment period, and a physician after-death assessment was completed for 213 residents; in the retrospective design, 117 residents were enrolled retrospectively after death.

Measurements

Advanced dementia (vs less advanced dementia) was defined as a Cognitive Performance Scale score (Morris *et al.* 1994) of 5 or 6 and a Global Deterioration Scale (Reisberg *et al.* 1982) score of 7 for comparability with other studies such as CASCADE (Mitchell *et al.* 2009). The physicians reported resident decisional capacity regarding preferred medical treatment as competent, partly competent or incompetent.

Physicians reported on decision making and context from the viewpoint of the treating physician. We

report whether residents had an advance directive upon admission. Physicians recorded the main care goal using the pre-structured items life prolongation, maintaining or improving of functioning, palliative and symptomatic care goal (van der Steen *et al.* 2013), other and no care goal. These main care goals are defined by the Dutch association of elderly care physicians and social geriatricians 'Verenso' (Verenso, 2007). Palliative and symptomatic goals both refer to comfort, quality of life and well-being but differ as to whether prolongation of life is desirable. Because this distinction is not well integrated in practice (van Soest-Poortvliet *et al.*, 2015) and unknown in other countries than the Netherlands, for analyses and presentation, we combined the palliative and the symptomatic care goals and used for the combined goals the term 'palliative care goal'. We report on treatment decisions and the reason for treatment. We distinguished the following six treatments or actions: at the time of death, resuscitation; during the last month of life, hospitalization; and during the last week, any antibiotics, intravenous fluids, subcutaneous fluid infusion and tube feeding. Further, physicians reported about decisions not to start treatment or to withdraw treatment shortly before death, including open-ended items to specify the treatment.

Statistical analyses

We report descriptive statistics and explored and reported any possible differences between residents with advanced and less advanced dementia. In all analyses, fewer than 5% of values were missing. Analyses were performed with SPSS 20.0.0.

Results

Characteristics

Less than half of the residents (43.2%) had advanced dementia upon death. A substantial minority of residents (36.5%) had been partly competent for decision making about medical treatment upon admission, and this decreased to 13.8% in the last week of life (Table 1). For residents with less advanced dementia, the proportion that had been (partly) competent for decision making was significantly larger than for residents with advanced dementia ($p < 0.001$ upon admission and $p < 0.001$ in the last week of life).

Treatment decision making and context

Of all residents, 4.9% (16/325) had an advance directive: for example, refusal of treatment such as no resuscitation, no artificial nutrition and hydration and no hospitalization. Of the 16 residents, four residents also had a wish for euthanasia. One of these residents had a wish for physician assisted death at baseline supported by an advance directive (formalized by a notary), and the physician commented that his/her death was due to physician-assisted suicide. Further, the attending physician found the resident competent for decision making in the last week. For the other three residents, a natural cause of death was reported.

Almost all residents had a palliative care goal on the day of death, and this referred to both residents with advanced dementia (94.2%) and residents with less advanced dementia (88.9%; no significant difference; Table 2). Resuscitation at the moment of death was rare (two residents; both had less advanced dementia), as was hospitalization in the last month (8.0%) and in the last week of life (1.5%). The most frequently reported reason for hospitalization was a fracture (33%; 7/21, 5 missing). Of the treatments, antibiotics were most commonly provided (24.2% in the last week). The treatment decisions did not differ between residents with advanced and less advanced dementia, except that residents with less advanced dementia received antibiotics significantly more often than residents with advanced dementia (Table 2). The most frequently reported reasons for antibiotic use were pneumonia (50.6%; 39/77 who received antibiotics) and urinary tract infection (33.8%; 26/77). Antibiotics were also provided for skin infections (3.9%; 3/77) and for other reasons (12%; 9/77). Four residents received tube feeding, and the reasons were as follows: vomiting due to an incident cerebrovascular accident, general malaise due to sepsis, one resident received tube feeding for a year because of a minimally conscious state and unknown. Fourteen residents received rehydration therapy, and the reasons for therapy were as follows: dehydration ($n=8$), pneumonia ($n=3$), diarrhoea ($n=1$) and one missing.

In 42.3% of the residents, decisions were made not to start treatment shortly before death, and in 53.7% of the residents, decisions were made to withdraw treatment shortly before death (Table 2). The type of decisions not to start treatment that were reported most frequently (in 135 residents) were decisions not to start with artificial nutrition and hydration ($n=96$) or antibiotics ($n=34$) and decisions not to

Table 1 Residents' characteristics

	Total N = 330		Residents with advanced dementia n = 139		Residents with less advanced dementia n = 183		Differences (t-test or Fisher's exact test) p-value
	n	%	n	%	n	%	
Age at death, mean (SD)	330	85.2 (7.4) ^a	139	84.1 (7.8)	183	85.8 (7.1)	Mean diff 1.7; 0.038
Ethnic origin other than Dutch	7	2.2	2	1.5	3	1.7	1.000
Advanced dementia 1 month before death	139	43.2 ^a					
Competent for decisions on preferred medical treatment							
Upon admission							<0.001
- Yes	6	1.9	0	0	5	2.8	
- In part	118	36.5	41	30.4	77	42.5	
- No	199	61.6	94	69.6	99	54.7	
In the last week of life							<0.001
- Yes	4	1.2	2	1.4	2	1.4	
- In part	45	13.8	3	2.2	42	23.2	
- No	276	84.9	134	96.4	137	75.7	

SD, standard deviation.

Data about the severity of the dementia was missing for eight residents.

^aAge at death and advanced dementia 1 month before death has also been reported elsewhere (Hendriks, Smalbrugge, Hertogh, & van der Steen 2016b).

Table 2 Decision making and context in the last phase of life

	Total N = 330		Residents with advanced dementia n = 139		Residents with less advanced dementia n = 183		Differences (Fisher's exact test) p-value
	n	%	n	%	n/N	%	
Advance directives							
Resident had an advance directive according to physician, upon admission	16	4.9	12	6.6	4	2.9	0.195
Care goals at the day of death							0.424
Life prolongation	3	0.9	0	0	2	1.1	
Maintaining or improving of functioning	10	3.1	2	1.4	8	4.4	
Palliative (aimed at well-being and quality of life)	296	91.1	131	94.2	160	88.9	
Global goals of treatment had not been assessed	13	4.0	1	0.7	2	1.1	
Other	3	0.9	5	3.6	8	4.4	
Resuscitation attempt	2	0.6	0	0.0	2	1.1	0.508
Hospitalization							
Admission last month of life	26	8.0	7	5.1	18	9.8	0.142
Admission last week of life	5	1.5	0	0.0		2.7	0.073
Specific treatment decisions in the last week of life							
Any antibiotics	78	24.2	24	17.6	52	28.9	0.024
Tube feeding	4	1.2	1	0.7	2	1.2	1.000
Rehydration (subcutaneous fluid infusion or intravenous fluids)	14	4.3	4	2.9	8	4.4	0.564
Decisions							
Any decision to not start treatment shortly before death	135	42.3	51	37.2	82	46.6	0.107
Any decision to withdraw treatment shortly before death	174	53.7	67	48.6	103	57.2	0.141

Data about the severity of the dementia was missing for eight residents.

hospitalize ($n = 17$). In case of withdrawing treatment, the type of treatments that were most frequently withdrawn was as follows (in 172 residents): withdrawing all oral drugs (e.g. in case of no longer able to swallow; $n = 134$), withdraw antibiotics ($n = 31$), other drugs ($n = 38$) and withdraw rehydration or tube feeding ($n = 7$).

Discussion

In this article, we describe end-of-life treatment decisions of nursing home residents dying with dementia in advanced and less advanced stages in long-term care settings in the Netherlands. We found in this study in which 91.1% of the residents had a palliative care goal

at the day of death (van Soest-Poortvliet *et al.* 2014) and low rates of interventions for residents with advanced dementia as well as for residents with less advanced dementia. Most residents did not have written advance directives when they were admitted to the long-term care facility. Also in Flanders, Belgium, only 8.4% of nursing home residents with dementia had an advance directive (De Gendt *et al.* 2013). In contrast with Europe, in the USA, written advance directives are common, with 71–72% directives reported in older people at the day of death (Silveira *et al.* 2014; Teno *et al.* 2007). The percentages of advance directives may be influenced by culture and type of organizational models.

Even though advance directives are rare in the Netherlands, earlier research found that the Netherlands, compared with the USA, has a culture in which forgoing life-prolonging medical interventions is accepted practice and in which quality of life is an important aspect in end-of-life decisions and often outweighs life prolongation (Helton *et al.* 2006). Consistently, we found low rates of life-prolonging interventions for residents with advanced dementia as well as for residents with less advanced dementia. Because most residents were not competent for decision making anymore, most discussions about end-of-life treatment decisions take place with proxy decision makers. There were multiple contact moments during nursing home stay between physicians, nurses and families in which care goals and treatment decisions were discussed (Hendriks *et al.* 2014). Resident's condition, wishes expressed by resident or family, family's willingness, family involvement and general nursing home policy guides physicians in initiating discussions (van Soest-Poortvliet *et al.* 2015).

We found a smaller proportion of residents with advanced dementia who were hospitalized in the last week of life than in the US CASCADE study of Mitchell *et al.* (2009) (0% were hospitalized in the Netherlands vs 9% in the USA in the last week of life) (Mitchell *et al.* 2009). Further, we found a smaller proportion of residents who received tube feeding or parenteral therapy. In the Netherlands, it is common practice not to start artificial nutrition and hydration in residents with dementia in a nursing home setting (Mehr *et al.* 2003; Pasma *et al.* 2004), because physicians may accept the reduction of food and fluids intake; they may consider this problem inherent to dementia and that interventions such as artificial food or fluids may not prolong survival or improve quality of life (Hendriks *et al.*, 2015; Pasma *et al.* 2004; Teno *et al.* 2012).

In our study, we found that antibiotics were the most frequently provided treatment. About a quarter

(24.2%) of the residents received antibiotics in the last week of life, and the most frequently reported reasons for antibiotic use were pneumonia and a urinary tract infection. The severity of dementia has been associated with forgoing antibiotic treatment in other studies (van der Maaden *et al.* 2016), and we also found that residents with advanced dementia received antibiotics less frequently than residents with less advanced dementia. Clinical decisions about prescribing or withholding antibiotics are surrounded by uncertainties and therefore difficult to make. Because effects of antibiotics on survival are probably limited to only few patients (van der Steen *et al.* 2012), especially in advanced dementia, and it remains unclear whether antibiotics actually enhance comfort (van der Steen 2011). Probable benefits of antibiotics must be weighed against potential adverse effects such as burdensome side effects, prolonging of the dying process and antibiotic resistance (van Buul *et al.* 2012; van der Maaden *et al.*, 2016; van der Maaden *et al.* 2015; van der Steen *et al.* 2012).

Health professionals often face dilemmas around whether the time has come not to start or to withdraw curative treatment because it does not add to quality of life (Goodman *et al.* 2015; Stewart *et al.* 1999). We found that decisions not to start treatment related mainly to artificial nutrition and hydration fluids, treatment with antibiotics and hospital transfers. We found that decisions to withdraw treatment related particularly to withdrawal of oral drugs shortly before death, possibly at the moment that residents were in very poor condition and were no longer able to swallow. A study from Norway in a general nursing home population also found that changes in drug treatment were made just at the day of death (Jansen *et al.* 2014).

Limitations

The present study has some limitations that warrant comment. First, the time frame 'shortly before death' for decision making was not defined. Second, we used data from both prospective and retrospective data collection. The reason for combining prospective data with retrospective data was because we could not follow up all cases until death (right censoring) with prospective data collection. This combination of perspectives avoids the risk of recall bias involved in fully retrospective studies and provides the benefit of understanding how the truncated longitudinal sample differs from a representative sample of residents who died with dementia in Dutch nursing homes (van der Steen *et al.* 2014b). Furthermore, we investigated

the differences between the two cohorts, and the only significant difference found was a higher proportion of withdrawing treatment in the prospective design (59.2%) than in the retrospective design (43.4%; $p=0.006$). Further, the proportion of residents with advanced dementia was lower in the prospective design (38.1%) than in the retrospective design (52.7%; $p=0.012$); (Hendriks et al. 2016b) however, we separately reported the results for residents with advanced and less advanced dementia.

Recommendation

End-of-life treatment decisions may affect the way that patients with dementia live their last months of life. Therefore, professional care givers should respond early to palliative care needs, which may help to enhance comfort. Discussions with patients and families about palliative care needs and how to deal with multimorbidity and drug therapy at the end of life in nursing home residents with dementia are of great importance. Future qualitative research, in particular participant observation research, may explore how elderly care physicians communicate with patients and families about treatment decisions in the context of advance care planning and may explore the rationale of care actions at the end of life and how the severity of the dementia plays a role.

Conclusion

Advance directives are rare in nursing home residents with dementia in the Netherlands.

Only few residents are hospitalized or undergo potentially burdensome interventions such as tube feeding or artificial nutrition and hydration. In addition, residents with advanced dementia as well as residents with less advanced dementia rarely undergo burdensome interventions. Physicians and families often agree upon a palliative care goal and are inclined to withhold and to forgo potentially burdensome life-prolonging treatment. This suggests that they feel that a palliative care approach is appropriate when death is expected in all stages of dementia in long-term care.

Conflict of interest

The study's sponsors had no role in the design, subject recruitment, data collection, analysis or preparation of the paper. None of the authors have conflicts of interest or dual commitments. The corresponding

author guarantees that all authors contributed substantially to the manuscript.

Key points

- Residents of Dutch long-term care facilities with advanced as well as less advanced dementia rarely undergo potentially burdensome life-prolonging treatment.
- Treatment decisions do not differ between residents with advanced and less advanced dementia, except that residents with less advanced dementia receive more antibiotics (than residents with advanced dementia).
- Decisions not to start or to withdraw treatment shortly before death mainly relate to artificial nutrition and hydration and medication.

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References

- Bouwstra H, Smalbrugge M, Hertogh CM. 2015. Physician treatment orders in Dutch nursing homes. *J Am Med Dir Assoc* 16(8): 715.
- De Gendt C, Bilsen J, Stichele RV, Deliens L. 2013. Advance care planning and dying in nursing homes in Flanders, Belgium: a nationwide survey. *J Pain Symptom Manage* 45(2): 223–234.
- Goodman C, Froggatt K, Amador S, Mathie E, Mayrhofer A. 2015. End of life care interventions for people with dementia in care homes: addressing uncertainty within a framework for service delivery and evaluation. *BMC Palliat Care* 14: 42.
- Helton MR, Cohen LW, Zimmerman S, van der Steen JT. 2011. The importance of physician presence in nursing homes for residents with dementia and pneumonia. *J Am Med Dir Assoc* 12(1): 68–73.
- Helton MR, van der Steen JT, Daaleman TP, Gamble GR, Ribbe MW. 2006. A cross-cultural study of physician treatment decisions for demented nursing home patients who develop pneumonia. *Ann Fam Med* 4(3): 221–227.
- Hendriks SA, Smalbrugge M, Hertogh CM, van der Steen JT. 2014. Dying with dementia: symptoms, treatment, and quality of life in the last week of life. *J Pain Symptom Manage* 47(4): 710–720.
- Hendriks SA, Smalbrugge M, Galindo-Garre F, Hertogh CM, van der Steen JT. 2015. From admission to death: prevalence and course of pain, agitation, and shortness of breath, and treatment of these symptoms in nursing home residents with dementia. *J Am Med Dir Assoc* 16(6): 475–481.
- Hendriks SA, Smalbrugge M, Hertogh CM, van der Steen JT. 2016a. Changes in care goals and treatment orders around the occurrence of health problems and hospital

- transfers in dementia: a prospective study. *J Am Geriatr Soc*. DOI:10.1111/jgs.14667[Epub ahead of print].
- Hendriks SA, Smalbrugge M, van Gageldonk-Lafeber AB, *et al.* 2016b. Pneumonia, intake problems, and survival among nursing home residents with variable stages of dementia in the Netherlands: Results from a prospective observational study. *Alzheimer Dis Assoc Disord*. DOI:10.1111/jgs.14667[Epub ahead of print].
- Hertogh CM. 2006. Advance care planning and the relevance of a palliative care approach in dementia. *Age Ageing* 35(6): 553–555.
- Hertogh CM, Ribbe MW. 1996. Ethical aspects of medical decision-making in demented patients: a report from the Netherlands. *Alzheimer Dis Assoc Disord* 10(1): 11–19.
- Houttekier D, Cohen J, Bilsen J, *et al.* 2010. Place of death of older persons with dementia. A study in five European countries. *J Am Geriatr Soc* 58(4): 751–756.
- Jansen K, Schaufel MA, Ruths S. 2014. Drug treatment at the end of life: an epidemiologic study in nursing homes. *Scand J Prim Health Care* 32(4): 187–192.
- Koopmans RT, Lavrijsen JC, Hoek JF, Went PB, Schols JM. 2010. Dutch elderly care physician: a new generation of nursing home physician specialists. *J Am Geriatr Soc* 58(9): 1807–1809.
- Mehr DR, van der Steen JT, Kruse RL, *et al.* 2003. Lower respiratory infections in nursing home residents with dementia: a tale of two countries. *Gerontologist* 43(Spec No 2): 85–93.
- Mitchell SL, Teno JM, Kiely DK, *et al.* 2009. The clinical course of advanced dementia. *N Engl J Med* 361(16): 1529–1538.
- Morris JN, Fries BE, Mehr DR, *et al.* 1994. MDS Cognitive Performance Scale. *J Gerontol* 49(4): M174–M182.
- Pasman HR, Onwuteaka-Philipsen BD, Ooms ME, *et al.* 2004. Forgoing artificial nutrition and hydration in nursing home patients with dementia: patients, decision making, and participants. *Alzheimer Dis Assoc Disord* 18(3): 154–162.
- Reisberg B, Ferris SH, de Leon MJ, Crook T. 1982. The Global Deterioration Scale for assessment of primary degenerative dementia. *Am J Psychiatry* 139(9): 1136–1139.
- Silveira MJ, Wiitala W, Piette J. 2014. Advance directive completion by elderly Americans: a decade of change. *J Am Geriatr Soc* 62(4): 706–710.
- Stewart AL, Teno J, Patrick DL, Lynn J. 1999. The concept of quality of life of dying persons in the context of health care. *J Pain Symptom Manage* 17(2): 93–108.
- Verenso, The Dutch Association of Elderly Care Physicians and Social Geriatricians. [Guideline: Concepts and Requirements of Care in relation to end-of-life decisions in long-term care]. [in Dutch]. 2007. Available from: <http://www.verenso.nl/assets/Uploads/Downloads/Handreikingen/Levensende-beleidsversie-070607.pdf> Accessed, 2015.
- Teno JM, Gozalo PL, Mitchell SL, *et al.* 2012. Does feeding tube insertion and its timing improve survival? *J Am Geriatr Soc* 60(10): 1918–1921.
- Teno JM, Gruneir A, Schwartz Z, Nanda A, Wetle T. 2007. Association between advance directives and quality of end-of-life care: a national study. *J Am Geriatr Soc* 55(2): 189–194.
- van Buul LW, van der Steen JT, Veenhuizen RB, *et al.* 2012. Antibiotic use and resistance in long term care facilities. *J Am Med Dir Assoc* 13(6): 568–513.
- van der Maaden T, Hendriks SA, de Vet HC, *et al.* 2015. Antibiotic use and associated factors in patients with dementia: a systematic review. *Drugs Aging* 32(1): 43–56.
- van der Maaden T, van der Steen JT, de Vet HC, Hertogh CM, Koopmans RT. 2016. Prospective observations of discomfort, pain, and dyspnea in nursing home residents with dementia and pneumonia. *J Am Med Dir Assoc* 17(2): 128–135.
- van der Steen JT. 2011. Prolonged life and increased symptoms vs prolonged dying and increased comfort after antibiotic treatment in patients with dementia and pneumonia. *Arch Intern Med* 171(1): 93–94.
- van der Steen JT, Lane P, Kowall NW, Knol DL, Volicer L. 2012. Antibiotics and mortality in patients with lower respiratory infection and advanced dementia. *J Am Med Dir Assoc* 13(2): 156–161.
- van der Steen JT, Onwuteaka-Philipsen BD, Knol DL, Ribbe MW, Deliens L. 2013. Caregivers' understanding of dementia predicts patients' comfort at death: a prospective observational study. *BMC Med* 11: 105.
- van der Steen JT, Radbruch L, Hertogh CM, *et al.* 2014a. White paper defining optimal palliative care in older people with dementia: a Delphi study and recommendations from the European Association for Palliative Care. *Palliat Med* 28(3): 197–209.
- van der Steen JT, Ribbe MW, Deliens L, Gutschow G, Onwuteaka-Philipsen BD. 2014b. Retrospective and prospective data collection compared in the Dutch End Of Life in Dementia (DEOLD) study. *Alzheimer Dis Assoc Disord* 28(1): 88–94.
- van Soest-Poortvliet MC, van der Steen JT, de Vet HC, *et al.* 2014. Factors related to establishing a comfort care goal in nursing home patients with dementia: a cohort study among family and professional caregivers. *J Palliat Med* 17(12): 1317–1327.
- van Soest-Poortvliet MC, van der Steen JT, Gutschow G, *et al.* 2015. Advance care planning in nursing home patients with dementia: A qualitative interview study among family and professional caregivers. *J Am Med Dir Assoc* 16(11): 979–989.
- Weuve J, Hebert LE, Scherr PA, Evans DA. 2014. Deaths in the United States among persons with Alzheimer's disease (2010–2050). *Alzheimers Dement* 10(2): e40–e46.