

Postprint Version	1.0
Journal website	http://pmj.sagepub.com/content/28/3/210
Pubmed link	http://www.ncbi.nlm.nih.gov/pubmed/24292158
DOI	10.1177/0269216313509128

This is a NIVEL certified Post Print, more info at <http://www.nivel.eu>

When do people with dementia die peacefully? An analysis of data collected prospectively in long-term care settings

MAAIKE L DE ROO¹ JENNY T VAN DER STEEN² FRANCISCA GALINDO GARRE³ NELE VAN DEN NOORTGATE⁴ BREGJE D ONWUTEAKA-PHILIPSEN¹ LUC DELIËNS^{1,5} ANNEKE L FRANCKE^{1,6} ON BEHALF OF EURO IMPACT

¹ Department of Public and Occupational Health, EMGO Institute for Health and Care Research, VU University Medical Center, Amsterdam, The Netherlands

² Department of General Practice & Elderly Care Medicine, EMGO Institute for Health and Care Research, VU University Medical Center, Amsterdam, The Netherlands

³ Department of Epidemiology and Biostatistics, VU University Medical Center, Amsterdam, The Netherlands

⁴ Department of Geriatrics, Ghent University Hospital, Ghent, Belgium

⁵ Vrije Universiteit Brussel, End-of-life Care Research Group Vrije Universiteit Brussel and Ghent University, Brussels, Belgium

⁶ NIVEL, Netherlands Institute for Health Services Research, Utrecht, The Netherlands

Corresponding author: Maaïke L De Roo, Department of Public and Occupational Health, EMGO Institute for Health and Care Research, VU University Medical Center, Van der Boechorststraat 7, 1081 BT Amsterdam, The Netherlands. Email: eol@vumc.nl

ABSTRACT

Background: Little is known about dying peacefully with dementia in long-term care facilities. Dying peacefully may be influenced by characteristics of the palliative care provided and characteristics of the long-term care setting. If so, dying peacefully may serve as a quality indicator for palliative care in dementia.

Aim: This study aims to describe whether residents with dementia in Dutch long-term care facilities die peacefully and to assess which characteristics of the resident, the palliative care provided and the facilities are associated with dying peacefully.

Design and Setting: We analysed existing data from the Dutch End of Life in Dementia study, collected between January 2007 and July 2010 in 34 long-term care facilities in the Netherlands. We used descriptive statistics and Generalised Estimating Equation models.

Results: The sample consisted of 233 residents with dementia. Family members indicated that the resident died peacefully in 56% of cases. This percentage ranged from 17% to 80% across facilities. Residents were more likely to die peacefully if they had an optimistic attitude, if family found that there were

enough nurses available and if residents died in facilities with a moderate (versus no) perceived influence of religious affiliation on end-of-life decision-making policies.

Conclusions: Only half of the residents with dementia in Dutch long-term care facilities die peacefully, as perceived by relatives. In addition to residents' optimistic attitude, facility characteristics are associated with dying peacefully, which suggests that 'the percentage of relatives who indicate that the patient died peacefully' can function as a quality indicator.

What is already known about the topic?

- Most research on dying peacefully has focused on personal factors influencing dying peacefully, for example, emotional well-being, religiousness and age.
- These factors are not always relevant for cognitively impaired patients, and no specific literature is available for cognitively impaired patients.
- 'The percentage of relatives who indicate that the patient died peacefully' has been suggested as a quality indicator for palliative care.

What this paper adds?

- Of residents with dementia in Dutch nursing homes, 56% died peacefully according to their family members.
- In addition to residents' optimistic attitude, the following facility characteristics were associated with dying peacefully: if family found that there were enough nurses available and when physicians perceived a moderate influence of religious affiliation on end-of-life decision-making policies.

Implications for practice, theory or policy?

- 'The percentage of relatives who indicate that the patient died peacefully' has potential as a quality indicator for palliative care.
- Further research is needed to evaluate whether the quality indicator discriminates between nursing homes and in other settings.

INTRODUCTION

It is a generally accepted belief that people wish to die peacefully. Nevertheless, literature on 'dying peacefully' is rather limited. The concept of 'dying peacefully' is broad, and it is often referred to as 'tranquillity',¹ which may be connected to various aspects of emotional and spiritual well-being,² such as feeling close to loved ones and feeling deep inner harmony.³ Furthermore, certain aspects of religiousness, such as regular church attendance and a proxy respondent's estimate of the salience of religion (the importance someone attaches to religion), have been shown to support a sense of peace in the last week of life.⁴ Being at peace at the end of life has also been associated with age, with younger patients reporting lower levels of being at peace.^{2,4}

Thus, so far, most research literature on factors influencing dying peacefully has focused on personal factors. However, emotional and spiritual well-being, which are related to dying peacefully, may be influenced by the care provided or by the facility in which care is provided. This means that in addition to personal characteristics, characteristics of the palliative care provided and of the care facilities may be related to a peaceful death, suggesting that the percentage of people dying peacefully can function as a quality indicator.^{5,6} Quality indicators are explicitly defined, measurable items referring to the outcomes, processes or structure of care.^{7,8} Quality indicators describe the quality of the palliative care provided and are increasingly being used to compare quality scores of different care providers in a structured way and to initiate quality improvements, where needed.^{5,9-13} In recent years, there has been increasing interest in quality indicators for palliative care.^{6,14} One example of a quality indicator referring to an outcome of palliative care is ‘the percentage of relatives who indicate that the patient died peacefully’.⁵

Despite the increase in people dying with or from dementia,¹⁵ little is known about whether people with dementia die peacefully; previous publications concerning the subject of a peaceful death mainly focused on non-cognitively impaired patients. In addition, previous studies did not link dying peacefully to the characteristics of the care provided or the care facilities, nor did they examine in that context whether the percentage of people dying peacefully could also function as an indicator of the quality of care. Furthermore, 92.3% of dementia-related deaths in the Netherlands occurred in nursing homes.¹⁶ Therefore, this article examines

1. Whether residents with dementia in Dutch long-term care facilities die peacefully according to their relatives;
2. Which characteristics of (a) the resident, (b) the palliative care provided and (c) the specific care facility are associated with dying peacefully.

METHODS

Design and setting

We used the dataset of the Dutch End of Life in Dementia (DEOLD) study. This study describes the quality of dying and satisfaction with end-of-life care and decision-making from the perspectives of family members and elderly care physicians.^{17,18} Long-term care facilities were recruited from all over the Netherlands. The sample was representative as to, for example, the family’s evaluation of the general quality of care provided. A total of 19 nursing-home organisations participated, covering a total of 34 long-term care facilities (28 nursing homes and 6 residential homes). Each of these nursing-home organisations employed its own team of qualified elderly care physicians (some physician teams covered more than one facility). In all, 17 participating nursing-home organisations collected data prospectively, meaning that residents were followed from admission to the nursing home until their death or the study conclusion. In addition to this prospective data collection, two organisations collected data retrospectively after death only, to increase the number of reports on decedents while avoiding the complicated logistics involved in prospective studies.¹⁷

Data collection

Data were collected between January 2007 and July 2010. In the prospective data collection, elderly care physicians and relatives completed written questionnaires at 8 weeks after admission, subsequently every 6 months and after death (2 months after death for relatives, and within 2 weeks for physicians). In the retrospective data collection, the long-term care facility invited relatives of eligible residents to participate 6 weeks after death. As in the prospective data collection, physicians completed the questionnaire 2 weeks after death. The relatives' response rates in the retrospective design (invited after death) were 55% and 58% in the prospective design (invited upon admission).¹⁷ A total of 337 residents died, of whom 248 residents had a complete after-death assessment by a physician and family member. For this study, we selected the 233 residents for whom the family member completed the question about whether their relative died peacefully. This sample comprised 173 decedents (74%) from the prospective data collection, and 60 decedents (26%) from the retrospective data collection.

Study population

The research subjects were residents who met the following inclusion criteria: (1) had been residing in a psychogeriatric ward or unit in a long-term facility supervised by qualified elderly care physicians, (2) had been diagnosed with dementia by a physician, (3) had been admitted for long-term care and (4) had a family representative who was able to understand and write Dutch or English.

Ethical approval

The protocol for the DEOLD study was approved by the Medical Ethics Committee of the VU University Medical Center in Amsterdam. In the prospective design, the long-term care facilities only collected data reported on residents whose families had consented upon admission to taking part. In the retrospective design, sending back the questionnaire (around 2 months after death) was viewed as providing informed consent, and families could object to coded information being transferred to the researchers.

Variables

The DEOLD study collected data about the resident, about the care process (on an individual resident level) and about the care facility, using questionnaires completed by elderly care physicians and family members. Data were selected from the DEOLD dataset if the data concerned variables that were considered to potentially have an influence on dying peacefully. These variables were selected by the authors since they concern palliative and spiritual care, patient-centred care, empathic approach and the structure and organisation of the facility. An overview of the variables used in this study, the respondents and the timing of the questions and the sources are provided in Box 1. The variables consisted of background characteristics, resident characteristics, care characteristics (on an individual level) and facility characteristics.

[Box 1.]

Data analysis

Statistical analyses were performed using IBM SPSS statistics software version 20.0 (IBM Corp., 2011, Armonk, NY, USA). First, frequencies and descriptive statistics were calculated for the study population, the outcome variable ‘dying peacefully’ and the potentially associated characteristics – the care characteristics and facility characteristics shown in Box 1. Second, missing data were imputed using multiple imputations,¹⁹ and 10 imputed datasets were generated with the Predictive Mean Matching method. Third, linear regression analyses were performed using the Generalised Estimating Equations (GEE) method to examine the association between dying peacefully and the potentially associated characteristics for each imputed dataset. Resident characteristics were used to adjust for case-mix differences between facilities. The GEE technique was used to account for correlated observations that emerge because of residents’ clustering in long-term care facilities. We used an independence matrix as the working correlation matrix. Finally, the results from all the imputed datasets were pooled into a unique set of parameters and standard errors. We tested the model both with and without ‘symptom burden’ as one of the adjustment factors, since this item may itself be influenced by the quality of care provided.

RESULTS

Dying peacefully

Family members thought that the resident had died peacefully in 56% of cases (‘completely’ or ‘quite a bit’ at peace in the last month of life) (Figure 1). On the other hand, 11% of family members said that their beloved one did not die peacefully at all. We calculated the percentage of residents dying peacefully per facility for the eight facilities that had 10 or more decedents. The percentage of residents who died peacefully varied between 17% and 80%, with most facilities having a percentage between 30% and 64% (Figure 2).

[FIGURE 1.][FIGURE 2.]

Resident characteristics and their association with dying peacefully

The majority of the 233 decedents were female (67%); the mean age at death was 85.7 years (Table 1). Less than half of the residents died with advanced dementia (46%), whereas dementia was mentioned as a direct or contributing cause of death in 87% of cases (Table 1). The majority of family members considered their resident as being neutral to optimistic (82.2%). Faith or spirituality was considered to be somewhat to very important to 71.3% of the residents (Table 1). The minimum reported score for the symptom burden was 0.5, the maximum was 40 and the mean symptom burden was 24.7 (standard deviation (SD) = 8.4) (Table 1). The majority of family members ($N = 233$) were female (60%); the mean age was 60.0 years. Most family members were children of the residents (65%) and 17% were spouses.

[TABLE 1.]

Resident characteristics were used as adjustment factors. In the multivariable analysis, having an optimistic attitude was found to be associated with dying peacefully in a stepwise fashion (B for ‘neither optimistic nor pessimistic attitude’ versus ‘pessimistic attitude’ = 0.40, $p = 0.04$; B for ‘optimistic attitude’ versus ‘pessimistic attitude’ = 0.53, $p < 0.001$). This was the only resident characteristic associated with dying peacefully. We noted no differences between the models with symptom burden as one of the adjustment factors and those without symptom burden.

Characteristics of the care provided and the facilities, and their association with dying peacefully

[TABLE 2.]

After correcting for resident characteristics in the univariable analysis, dying peacefully is positively associated with the following care characteristics: adequate personal attention (in a stepwise fashion, Table 3), adequate personal care (B for ‘strongly agree’ = 0.44, $p = 0.048$), always treated with respect ($B = 0.42$, $p = 0.017$) and always treated with kindness ($B = 0.54$, $p = 0.002$; Table 3). Regarding characteristics of the long-term care facilities, when family members found that enough nurses were present, this was positively associated with the families’ perception that the resident died peacefully ($B = 0.55$, $p < 0.001$; Table 3).

[TABLE 3.]

In the multivariable analysis, none of the care characteristics was significantly associated with dying peacefully. Two facility characteristics were positively associated with dying more peacefully: a moderate influence of religious affiliation on the facility’s end-of-life decision-making policies ($B = 0.41$, $p = 0.03$) and family members’ opinion that there were enough nurses available ($B = 0.44$, $p = 0.005$).

DISCUSSION

Only 56% of residents ($N = 233$) in Dutch long-term care facilities died peacefully according to their relatives. This percentage differs between the different long-term care facilities, ranging from 17% to 80%, which means that the quality indicator ‘the percentage of relatives who indicate that the patient died peacefully’ could reveal quality differences between different facilities. Most facilities had a percentage between 30% and 64%.

Residents having a neutral (neither optimistic nor pessimistic) or optimistic attitude were more likely to die peacefully than people with a pessimistic attitude. Surprisingly, none of the selected care characteristics we had expected to have an association with dying peacefully had significant associations with dying peacefully in the multivariable model. Adequate personal attention, always being treated with respect and always being treated with kindness were associated with dying

peacefully in the univariable model (correcting for resident characteristics), which suggests that these care characteristics are dependent on other care and facility characteristics. Two facility characteristics were associated with dying peacefully: residents were more likely to die peacefully in a facility where elderly care physicians perceived a moderate influence of religious affiliation on end-of-life decision-making policies and in a facility where their relatives found that there were enough nurses available.

Our results show that specific facility characteristics relate to dying peacefully, in addition to the influence of the residents' personal characteristics. This suggests that specific facility characteristics do indeed matter and make a difference in the quality of care provided. Although we can never fully exclude other potential aspects that play a role in the revealed differences of dying peacefully between different facilities, it is assumable that these differences are indicators of differences in the quality of care provided, since we saw that certain facility and care characteristics are related to differences in the percentage of residents dying peacefully.

To our knowledge, there are no previous studies that describe characteristics of the care provided or the care facilities that are associated with dying peacefully. Therefore, we are not able to draw from or compare with existing evidence. We only explored one quality indicator here, and although this single quality indicator highlights an important outcome of the quality of palliative care, it highlights only one aspect of care. Therefore, it should preferably be used in combination with other quality indicators to give a broader perspective on the palliative care provided.

We did not find an association of dying peacefully with symptom burden. The inclusion or exclusion of symptom burden in the model did not affect other associations. We presumed that this item could itself be influenced by the quality of care provided, but it had no effect on revealing other associated characteristics. This suggests that family members perceive dying peacefully with dementia as a concept that is distinct from symptom burden. Measuring dying peacefully and symptom burden in this patient population by using family members as proxies covers two different outcomes of palliative care, each of which reflects a different aspect of the quality of palliative care provided.

Limitations and strengths

This study is, as far as we know, the first to describe dying peacefully in a dementia population. We considered it a benefit to use the existing DEOLD dataset, since we were able to evaluate dying peacefully and its potential as a quality indicator without having to collect new data. The questionnaire item in the DEOLD study referred to whether the resident was 'at peace' in the last month of life and was considered sufficiently close to 'dying peacefully' as phrased in the original quality indicator developed by Claessen et al.⁵ It was an advantage that we could use the existing data of a validated instrument to measure dying peacefully in a population with dementia.

However, the original limitations are also present in this study. The DEOLD study comprised both a prospective and retrospective data collection, but this did not affect

the associations we found. For the facility characteristics, we had to rely on the opinion of the coordinating elderly care physician, while for the outcome ‘dying peacefully’ we relied on the observations of the family members. However, we have no data on what kind of signs or expressions of the resident families use to discern whether a patient died peacefully. We recommend future research to shed light on the signs or expressions by the patient that explain families’ judgement of dying peacefully. Since we did not have high number of decedents per facility, we were not able to perform a case-mix adjustment, that is, correcting the percentage of residents dying peacefully per facility, and we recommend taking this into account in future research.

CONCLUSION

Our finding that dying peacefully is related to care facility characteristics highlights its potential as a quality indicator for measuring the quality of palliative care provided. However, before using this quality indicator in practice, we recommend research be done to evaluate the discriminative power of the indicator (whether it can indeed reveal differences between care facilities, taking into account the patient case mix), and to test it in other settings.

Acknowledgments

EURO IMPACT aims to develop a multidisciplinary, multi-professional and inter-sectorial educational and research training framework for palliative care research in Europe. EURO IMPACT is coordinated by Prof Luc Deliens and Prof Lieve Van den Block of the End-of-Life Care Research Group, Ghent University & Vrije Universiteit Brussel, Brussels, Belgium.

EURO IMPACT collaborators: Van den Block Lieve,^a Meeussen Koen,^a Cohen Joachim,^a Pardon Koen,^a Francke Anneke,^b Onwuteaka-Philipsen Bregje,^b Pasman Roeline,^b Deliens Luc,^{a,b} Harding Richard,^{c,d} Higginson Irene J,^{c,d} Brearley Sarah,^e Payne Sheila,^e Kaasa Stein,^f Caraceni Augusto,^g Costantini Massimo,^h Miccinesi Guido,ⁱ Pautex Sophie,^j Linden Karen.^k

^aEnd-of-Life Care Research Group, Ghent University and Vrije Universiteit Brussel, Brussels, Belgium; ^bVU University Medical Center, EMGO Institute for Health and Care Research, Amsterdam, The Netherlands; ^cCicely Saunders Institute, King’s College London, London, UK; ^dCicely Saunders International, London, UK; ^eInternational Observatory on End-of-Life Care, Lancaster University, Lancaster, UK; ^fNorwegian University of Science and Technology, Trondheim, Norway; ^gEAPC Research Network, Trondheim, Norway; ^hRegional Palliative Care Network, IRCCS AOU San Martino-IST, Genoa, Italy; ⁱCancer Research and Prevention Institute, Florence, Italy; ^jEUGMS European Union Geriatric Medicine Society, Geneva, Switzerland; ^kSpringer Science and Business Media, Houten, The Netherlands

REFERENCES

1. Roberts KT, Aspy CB . Development of the serenity scale. *J Nurs Meas*1993; 1(2): 145–164.
2. Steinhauser KE, Voils CI, Clipp EC, et al . 'Are you at peace?': one item to probe spiritual concerns at the end of life. *Arch Intern Med*2006; 166(1): 101–105.
3. Ray A, Block SD, Friedlander RJ, et al . Peaceful awareness in patients with advanced cancer. *J Palliat Med*2006; 9(6): 1359–1368.
4. Braam AW, Klinkenberg M, Deeg DJH . Religiousness and mood in the last week of life: an explorative approach based on after-death proxy interviews. *J Palliat Med*2011; 14(1): 31–37.
5. Claessen SJJ, Francke AL, Belarbi HE, et al . A new set of quality indicators for palliative care: process and results of the development trajectory. *J Pain Symptom Manage*2011; 42(2): 169–182.
6. De Roo ML, Leemans K, Claessen SJJ, et al . Quality indicators for palliative care: update of a systematic review. *J Pain Symptom Manage*2013; 46(4): 556–572.
7. Campbell SM, Braspenning J, Hutchinson A, et al . Research methods used in developing and applying quality indicators in primary care. *BMJ*2003; 326(7393): 816–819.
8. Donabedian A. The quality of care. How can it be assessed?*JAMA*1988; 260(12): 1743–1748.
9. Campbell SM, Roland MO, Buetow SA . Defining quality of care. *Soc Sci Med*2000; 51(11): 1611–1625.
10. Bowman KW, Martin DK, Singer PA . Quality end-of-life care. *J Eval Clin Pract*2000; 6(1): 51–61.
11. Rosenfeld K, Wenger NS . Measuring quality in end-of-life care. *Clin Geriatr Med*2000; 16(2): 387–400.
12. Davies E, Higginson I (eds). *The solid facts: palliative care*. Geneva: World Health Organization, 2004.
13. Ferrell B, Connor SR, Cordes A, et al . The national agenda for quality palliative care: the National Consensus Project and the National Quality Forum. *J Pain Symptom Manage*2007; 33(6): 737–744.
14. Pasman HR, Brandt HE, Deliens L, et al . Quality indicators for palliative care: a systematic review. *J Pain Symptom Manage*2009; 38(1): 145–156.
15. World Health Organization (WHO). *Dementia: a public health priority*. http://www.who.int.proxy.library.uu.nl/mental_health/publications/dementia_report_2012/en/index.html (2012, accessed 15 May 2013).
16. Houttekier D, Cohen J, Bilsen J, et al . Place of death of older persons with dementia. A study in five European countries. *J Am Geriatr Soc*2010; 58(4): 751–756.
17. Van der Steen JT, Ribbe MW, Deliens L, et al . Retrospective and prospective data collection compared in the Dutch End of Life in Dementia (DEOLD) study. *Alzheimer Dis Assoc Disord*. Epub ahead of print 28April2013. DOI: 10.1097/WAD.0b013e318293b380.
18. Van der Steen JT, Deliens L, Ribbe MW, et al . Selection bias in family reports on end of life with dementia in nursing homes. *J Palliat Med*2012; 15(12): 1292–1296.
19. Van Buuren S . *Flexible imputation of missing data*. Boca Raton, FL: Chapman & Hall/CRC Press, 2012.
20. Munn JC, Zimmerman S, Hanson LC, et al . Measuring the quality of dying in long-term care. *J Am Geriatr Soc*2007; 55(9): 1371–1379.
21. Volicer L, Hurley AC, Blasi ZV . Characteristics of dementia end-of-life care across care settings. *Am J Hosp Palliat Care*2003; 20(3): 191–200.
22. Volicer L, Hurley AC, Blasi ZV . Scales for evaluation of end-of-life care in dementia. *Alzheimer Dis Assoc Disord*2001; 15(4): 194–200.
23. Mitchell SL, Kiely DK, Jones RN, et al . Advanced dementia research in the nursing home: the CASCADE study. *Alzheimer Dis Assoc Disord*2006; 20(3): 166–175.
24. Morris JN, Fries BE, Mehr DR, et al . MDS cognitive performance scale. *J Gerontol*1994; 49(4): M174–M182.

25. Reisberg B, Ferris SH, de Leon MJ, et al . The Global Deterioration Scale for assessment of primary degenerative dementia. *Am J Psychiatry*1982; 139(9): 1136–1139.
26. Tenó J . TIME: Toolkit of Instruments to Measure End-of-life care. <https://as800.chcr.brown.edu/pcoc/Esum.htm> (2004, accessed 15 May 2013).
27. Tenó JM, Clarridge BR, Casey V, et al . Family perspectives on end-of-life care at the last place of care. *JAMA*2004; 291(1): 88–93.
28. HughesC, Lloyd-WilliamsM, SachsGA Hertogh C. Advance care planning and palliative care in the dementia: a view from the Netherlands. In: HughesC, Lloyd-WilliamsM, SachsGA (eds) Supportive care for the person with dementia. New York: Oxford University Press, Inc., 2010, pp. 271–280.
29. Verbeek H, van Rossum E, Zwakhalen SMG, et al . Small, homelike care environments for older people with dementia: a literature review. *Int Psychogeriatr*2009; 21(2): 252–264.
30. Verbeek H, Zwakhalen SMG, van Rossum E, et al . Small-scale, homelike facilities in dementia care: a process evaluation into the experiences of family caregivers and nursing staff. *Int J Nurs Stud*2012; 49(1): 21–29.

TABLES AND FIGURES

Box 1. Overview of the variables used.

Domains and variables	Item and source	Respondent, timing
Background characteristics	- Of the resident: age, gender, type of dementia and cause of death - Of the family member: age and gender	Physician – after death
		Family member – after death
Resident characteristics		
Dying peacefully (outcome)	QOD-LTC item ‘he/she appeared to be at peace’. ²⁰ Original response options: <i>not at all, a little bit, a moderate amount, quite a bit, completely</i> . For analyses, we combined ‘quite a bit’ and ‘completely’	Family member – after death
Symptom burden	Based on SM-EOLD, ^{1,22} <i>frequencies of pain, shortness of breath, skin breakdown, calm, depression, fear, anxiety, agitation, resistiveness to care</i> . For analyses, we calculated a total score after exclusion of the item ‘calm’ (the only positive item, other items refer to symptoms)	Physician – after death
Importance of faith or spirituality	CASCADE item ‘importance of faith’ ²³	Family member – baseline study
Optimistic attitude	Developed for purpose of the DEOLD, ^{16,17} <i>Did your family member generally have an optimistic or a more pessimistic attitude?</i> Response options: ‘pessimistic; neither pessimistic, nor optimistic; optimistic’	Family member – baseline study

(Box 1 Continued)

(Box 1 Continued)

Domains and variables	Item and source	Respondent, timing
Advanced dementia	Developed for purpose of the DEOLD, ^{16,17} <i>Advanced dementia was defined using two instruments: Cognitive Performance Scale (CPS) 5 or 6²⁴ and Global Deterioration Scale (GDS) 7²⁵</i>	Physician – after death
Relation to family member	For analyses, a pre-structured listing of 7 response options was combined into 'spouse, son/daughter, other'	Family – after death
Care characteristics		
Adequate personal attention	Developed for the purpose of the DEOLD, ^{16,17} <i>I feel that my relative/loved one receives adequate personal attention</i>	Family – after death
Adequate personal care	Developed for the purpose of the DEOLD, ^{16,17} <i>I feel that my relative/loved one receives good personal care (washing, brushing teeth, etc.)</i>	Family – after death
Always treated with respect	TIME item 'How often was (he/she) treated with respect by those who were taking care of (him/her)'. ^{26,27} For analyses, response options were dichotomised into 'always' = always; 'usually, sometimes, or never' = not always	Family – after death
Always treated with kindness	TIME item 'How often was (he/she) treated with kindness by those who were taking care of (him/her)'. ^{26,27} For analyses, response options were dichotomised into 'always' = always; 'usually, sometimes, or never' = not always	Family – after death
Care goal priority for palliative or symptomatic care	<i>Which of the following care goals had priority on the day the resident died?</i> ²⁸ Original response options: <i>curative care goal, maintaining or improving function, palliative care goal, symptomatic care goal.</i> ³ For analyses, options were dichotomised into 'not having a palliative or symptomatic care goal'; 'having a palliative or symptomatic care goal'	Physician – after death
Spiritual care provided at the end of life	Developed for the purpose of the DEOLD, ^{16,17} <i>Did the resident receive spiritual care (pastoral care involving the last sacraments or another last rite) shortly before death?</i>	Physician – after death
Resident lived in a small-scale living facility (6–8 residents ^{29,30})	<i>Was the resident living in a small-scale living facility?</i>	Physician – conclusion study
Facility characteristics		
Number of psychosocial interventions provided (including the last phase of life)	Developed for the purpose of the DEOLD, ^{16,17} <i>Which psychosocial interventions are provided to residents with dementia including in the last phase of life?</i> Pre-structured listing from which the number of relevant activities for the end-of-life was calculated	Physician – conclusion study
Religious affiliation is reflected in end-of-life decision-making policies	Developed for the purpose of the DEOLD, ^{16,17} <i>To what degree do you feel the religious affiliation of your nursing home is reflected in policy regarding end-of-life decisions?</i>	Physician – midway study
Enough nurses available	Developed for the purpose of the DEOLD, ^{16,17} <i>Do you feel that enough nurses are available on the psychogeriatric wards at this moment?</i> For analyses, response options were dichotomised into 'yes, more than enough'; 'yes, just enough' = enough staff; 'no, not enough' = not enough staff	Physician – conclusion study
Enough physicians available	Developed for the purpose of the DEOLD, ^{16,17} <i>Do you feel that enough physicians are available on the psychogeriatric wards at this moment?</i> For analyses, response options were dichotomised into 'yes, more than enough'; 'yes, just enough' = enough staff; 'no, not enough' = not enough staff	Physician – conclusion study
Quality of the nurses is adequate	Developed for purpose of the DEOLD, ^{16,17} <i>Do you feel the quality of nurses is adequate?</i>	Physician – conclusion study

(Box 1 Continued)

(Box 1 Continued)

Domains and variables	Item and source	Respondent, timing
Family finds enough nurses available	Developed for the purpose of the DEOLD, ^{16,17} <i>Do you feel that enough nurses were available in the last week of life?</i> For analyses, response options were dichotomised into 'yes, more than enough'; 'yes, just enough' = enough staff; 'no, not enough' = not enough staff	Family – after death

QOD-LTC: Quality of Dying in Long-Term Care;²⁰ SM-EOLD: Symptom Management–End-of-Life in Dementia;^{21,22} CASCADE: Choices, Attitudes, and Strategies for Care of Advanced Dementia at the End-of-Life;²³ DEOLD: Dutch End of Life in Dementia;^{16,17} TIME: Toolkit of Instruments to Measure End-of-life care.^{26,27}

^aThe following definitions were used – Palliative care goal: a care goal aimed primarily at safeguarding optimal well-being and an acceptable quality of life of the patient with dementia. This goal is achieved by treatment of other complaints, co-morbidity, symptoms and complications resulting from the dementia. Extending life as a potential side effect of this treatment is not contraindicated – or is even part of the care goal. Symptomatic care goal: a care goal aimed primarily at safeguarding optimal well-being and an acceptable quality of life of the patient with dementia. This goal is achieved by treatment of other complaints, co-morbidity, symptoms and complications resulting from the dementia. A life-extending side effect as a result of medical treatment aimed at this goal is undesirable.

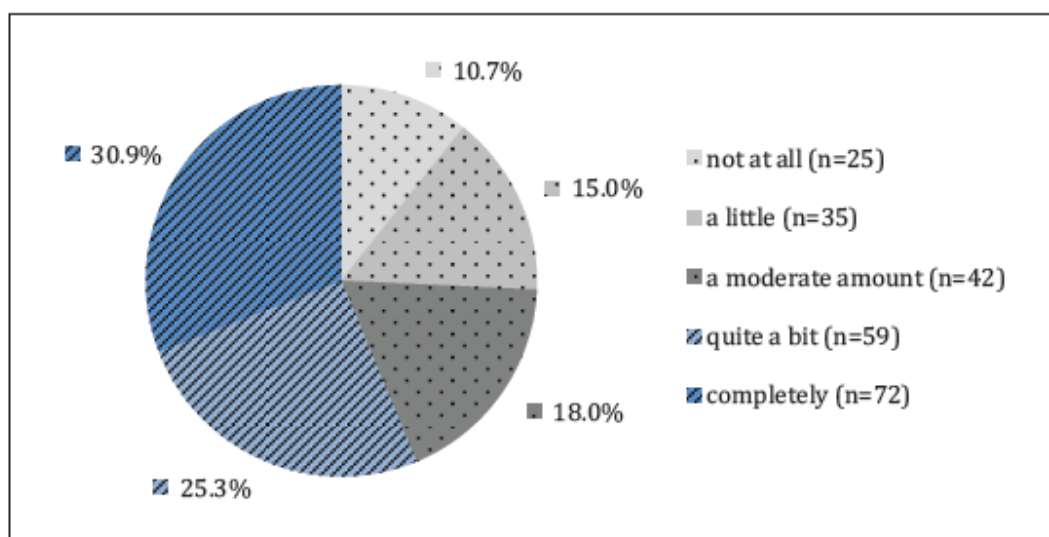


Figure 1. Percentage dying peacefully in residents with dementia in long-term care facilities (N = 233).

'Not at all', 'a little' and 'a moderate amount' were seen as not dying peacefully; 'quite a bit' and 'completely' were seen as dying peacefully.

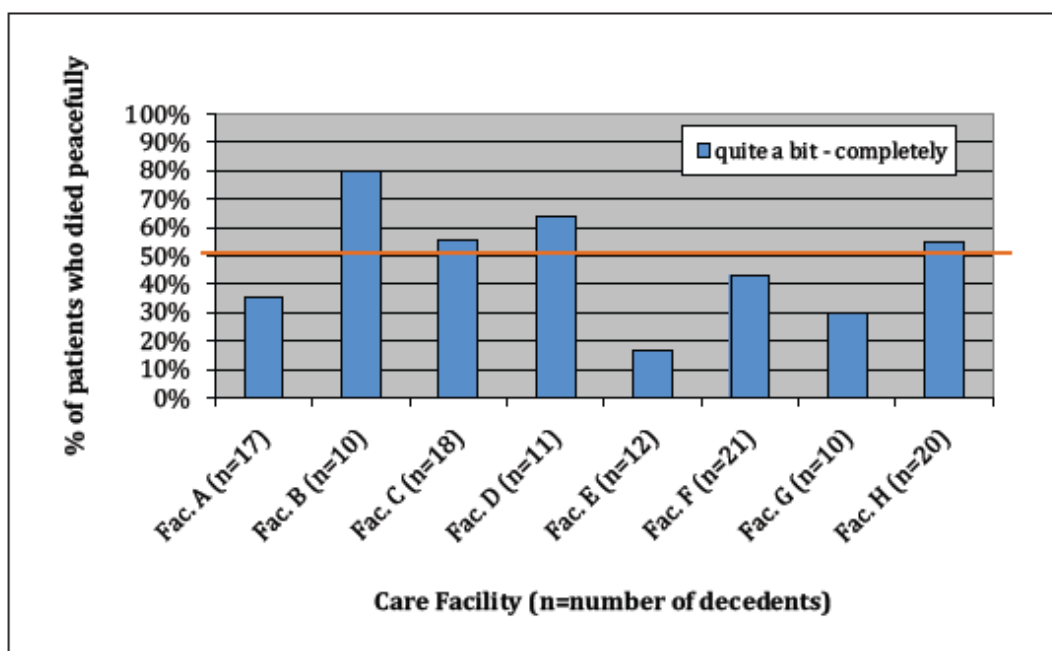


Figure 2. Percentage of residents who died peacefully per facility.^a

^a Facilities (Fac.) are shown in this figure only if they had 10 or more decedents.

Table 1. Characteristics of the residents.

	Residents (N = 233) %
Female sex	66.5
Age at death (mean (SD)) ^a	85.7 (7.2)
Type of dementia ^b	
Alzheimer	41.0
Vascular dementia	27.3
Lewy Body dementia	5.7
Alzheimer's and vascular dementia	16.7
All other combinations	9.3
Advanced dementia ^c	46.4
(Contributing) cause of death ^d	
Dementia	87.1
Cardiovascular disease	43.8
Dehydration	42.9
Respiratory infection	24.6
Other infections	11.6
Cachexia	23.2
Malignancy	8.9
Importance of faith or spirituality ^e	
Not at all important	28.7
Somewhat important	34.1
Very important	37.2
Optimistic attitude ^f	
Pessimistic	17.8
Neither pessimistic nor optimistic	42.6
Optimistic	39.6
Symptom burden (mean (SD)) ^g	24.7 (8.4)

SD: standard deviation.

^a4 missing values.

^b6 missing values.

^cAdvanced dementia was defined as Global Deterioration Scale stage 7 and a Cognitive Performance Scale of 5 or 6; 9 missing values.

^dWe listed all causes of death with a minimum of 5%; 'cause of death' refers to all causes of death which were listed anywhere on the death certificate, this includes both the direct cause of death and contributing causes of death; 9 missing values.

^e10 missing values.

^f3 missing values.

^gThe possible scores range from 0 to 40, with a higher score indicating better symptom control; 20 missing values.

Table 2. Characteristics of the care provided and of the long-term care facilities.

	Residents (N = 233), n (%)
Care characteristics	
Adequate personal attention ^{a,c}	
Disagree	35 (15.3)
Agree	110 (48.0)
Strongly agree	84 (36.7)
Adequate personal care (e.g. washing and brushing teeth) ^{b,c}	
Disagree	32 (14.0)
Agree	118 (51.8)
Strongly agree	78 (34.2)
Always treated with respect ^c	191 (83.4)
Always treated with kindness ^{d,c}	189 (83.3)
Care goal priority for palliative or symptomatic care ^{e,§}	203 (89.8)
Spiritual care provided at the end of life ^{f,§}	60 (27.3)
Resident lived in a small-scale living facility ^{g,§}	63 (27.2)
Facility characteristics	
Number of psychosocial interventions provided (including the last phase of life) ^{h,§}	
No interventions	27 (11.7)
1 intervention	0 (0.0)
2 interventions	19 (8.2)
3 interventions	114 (49.4)
4 interventions	71 (30.7)
5 interventions	0 (0.0)
Religious affiliation is reflected in end-of-life decision-making policies ^{i,§}	
No influence or no religious affiliation	131 (60.1)
Moderate influence	64 (29.4)
Strong influence	23 (10.6)
Enough nurses available ^{j,§}	103 (54.8)
Enough physicians available ^{k,§}	131 (69.7)
Quality of nurses is adequate ^{l,§}	
Inadequate	42 (22.3)
Just adequate	86 (45.7)
More than adequate	60 (31.9)
Family finds enough nurses available ^{m,c}	196 (86.7)

^a4 missing values.

^b5 missing values.

^c4 missing values.

^d6 missing values.

^e7 missing values.

^fShortly before death, pastoral care was provided involving the last sacraments, or another last rite; 13 missing values.

^gIn small-scale living facilities six to eight residents live together in a homelike environment, where they take part in normal daily activities;^{29,30} 1 missing value.

^hThese psychosocial interventions had to be chosen from a pre-structured listing, and could only be chosen if they were offered to residents with dementia including the last phase of life; 2 missing values.

ⁱ15 missing values.

^j45 missing values.

^k45 missing values.

^l45 missing values.

^m7 missing values.

^cAnswered by the family member.

[§]Answered by the physician.

Table 3. Univariable and multivariable models dying peacefully in long-term care facility residents with dementia (N = 233).

Characteristics	Univariable, B (95% CI)	Multivariable, B (95% CI)
<i>Care characteristics</i>		
Adequate personal attention		
Disagree	reference	reference
Agree	0.42 (0.1; 0.7)**	0.20 (-0.1; 0.6)
Strongly agree	0.56 (0.3; 0.9)*	0.22 (-0.2; 0.7)
Adequate personal care		
Disagree	reference	reference
Agree	0.24 (-0.1; 0.6)	-0.20 (-0.6; 0.2)
Strongly agree	0.44 (0.0; 0.9)*	-0.08 (-0.7; 0.5)
Always treated with respect	0.42 (0.1; 0.8)*	0.07 (-0.3; 0.5)
Always treated with kindness	0.54 (0.2; 0.9)*	0.30 (-0.2; 0.8)
No care goal priority for palliative/symptomatic care	-0.02 (-0.5; 0.4)	0.13 (-0.3; 0.5)
Spiritual care provided at the end of life ^a	0.05 (-0.3; 0.4)	0.03 (-0.3; 0.4)
Resident lived in a small-scale living facility	0.22 (-0.1; 0.5)	0.20 (-0.2; 0.6)
<i>Facility characteristics</i>		
Number of psychosocial interventions provided (including the last phase of life) ^b	0.04 (-0.1; 0.2)	0.04 (-0.1; 0.2)
Religious affiliation is reflected in end-of-life decision-making policies		
No influence or no religious affiliation	reference	reference
Moderate influence	0.24 (-0.2; 0.6)	0.41 (0.1; 0.8)*
Strong influence	0.01 (-0.3; 0.5)	0.07 (-0.3; 0.5)
Enough nurses available	0.10 (-0.3; 0.5)	-0.05 (-0.5; 0.4)
Enough physicians available	0.19 (-0.2; 0.5)	0.12 (-0.4; 0.7)
Quality of nurses is adequate		
Inadequate	reference	reference
Just adequate	0.13 (-0.2; 0.5)	0.02 (-0.5; 0.6)
More than adequate	0.23 (-0.2; 0.7)	0.02 (-0.6; 0.7)
Family finds enough nurses available	0.55 (0.3; 0.8)**	0.44 (0.1; 0.7)*

CI: confidence interval.

The following characteristics of the residents were used in all analyses as adjusting factors: age of the resident, gender of the resident, symptom burden of the resident, importance of faith or spirituality, optimistic attitude of the resident, advanced dementia and relation to the family member. B regression coefficients marked in bold with * are significant at $p < 0.05$.

B regression coefficients marked in bold with ** are significant at $p < 0.001$.

^aShortly before death, pastoral care was provided involving the last sacraments or another last rite.

^bPsychosocial interventions were selected from a pre-structured listing indicating those offered to residents with dementia including the last phase of life.