



Universiteit
Leiden

The Netherlands

Quality until we die: quality of life and quality of dying in nursing home residents with dementia

Klapwijk, M.S.

Citation

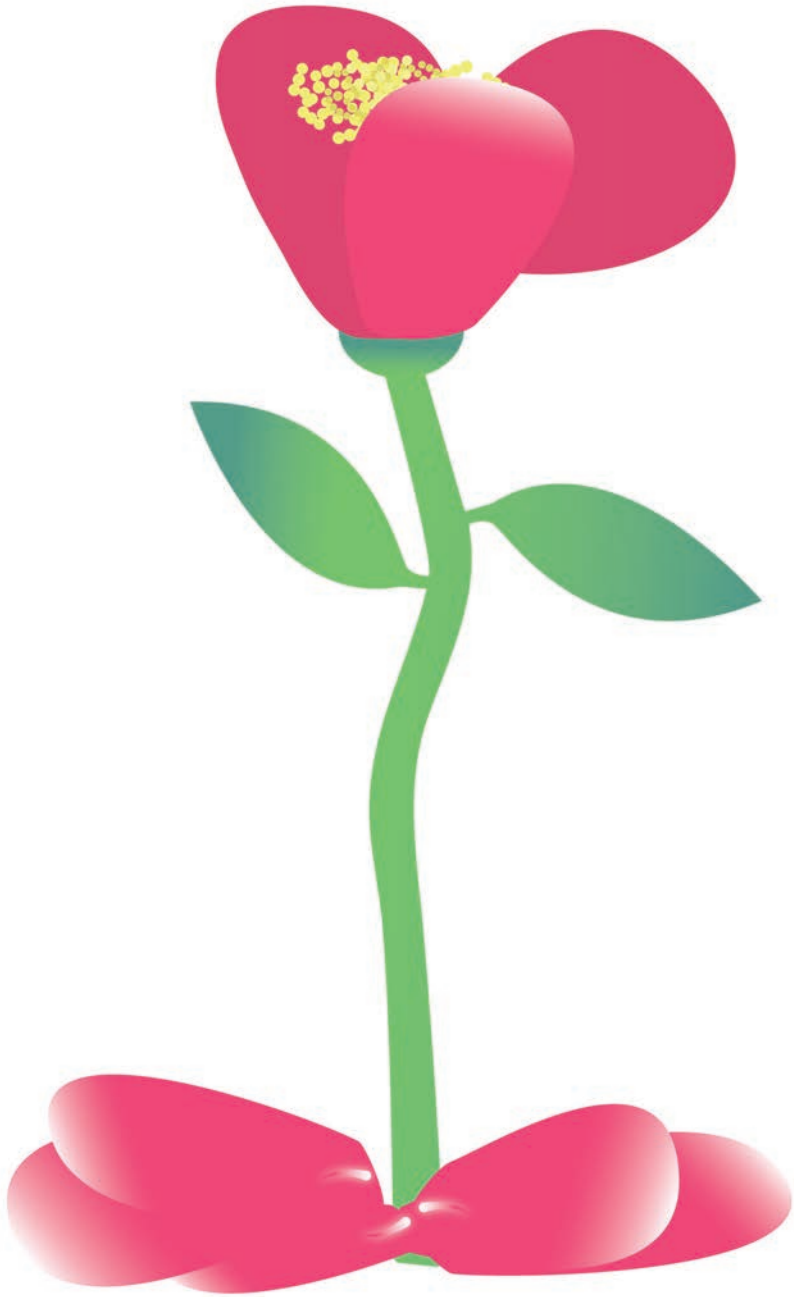
Klapwijk, M. S. (2022, January 20). *Quality until we die: quality of life and quality of dying in nursing home residents with dementia*. Retrieved from <https://hdl.handle.net/1887/3254632>

Version: Publisher's Version

License: [Licence agreement concerning inclusion of doctoral thesis in the Institutional Repository of the University of Leiden](#)

Downloaded from: <https://hdl.handle.net/1887/3254632>

Note: To cite this publication please use the final published version (if applicable).



Chapter 6

Trends in quality of care and dying perceived by family caregivers of nursing home residents with dementia 2005-2019

Maartje S. Klapwijk, Sascha R. Bolt, Jannie A. (Nienke) Boogaard, Maud ten Koppel, Marie-José H.E. Gijsberts, Carolien van Leussen, Anne-Mei The, Judith M.M. Meijers, Jos M.G.A. Schols, H. Roeline W. Pasman, Bregje D. Onwuteaka-Philipsen, Luc Deliens, Lieve Van den Block, Bart Mertens, Henrica C.W. de Vet, M.A.A. Caljouw, Wilco P. Achterberg, Jenny T. van der Steen

Pall Med. 2021 Aug 28;2692163211030831. doi: 10.1177/02692163211030831

Abstract

Background

Dementia palliative care is increasingly subject of research and practice improvement initiatives.

Aim

To assess any changes over time in the evaluation of quality of care and quality of dying with dementia by family caregivers.

Design

Combined analysis of eight studies with bereaved family caregivers' evaluations 2005-2019.

Setting/participants

Family caregivers of nursing home residents with dementia in the Netherlands (n=1189) completed the End-of-Life in Dementia Satisfaction With Care (EOLD-SWC; quality of care) and Comfort Assessment in Dying (EOLD-CAD, four subscales; quality of dying) instruments. Changes in scores over time were analysed using mixed models with random effects for season and facility and adjustment for demographics, prospective design and urbanized region.

Results

The mean total EOLD-SWC score was 33.40 (SD 5.08) and increased by 0.148 points per year (95% CI, 0.052 to 0.244; adjusted 0.170 points 95% CI, 0.055 to 0.258). The mean total EOLD-CAD score was 30.80 (SD 5.76) and, unadjusted, there was a trend of decreasing quality of dying over time of -0.175 points (95% CI, -0.291 to -0.058) per year increment. With adjustment, the trend was not significant (-0.070 EOLD-CAD total score points, 95% CI, -0.205 to 0.065) and only the EOLD-CAD subscale 'Well being' decreased.

Conclusion

We identified divergent trends over 14 years of increased quality of care, while quality of dying did not increase and well-being in dying decreased. Further research is needed on what well-being in dying means to family. Quality improvement requires continued efforts to treat symptoms in dying with dementia.

Key statements

What is already known about the topic?

- Dementia is an incurable condition and in Western countries, most people with dementia die in nursing homes.
- The knowledge base concerning palliative care for people with dementia has expanded.
- Bereaved family caregivers' experiences and perceptions of the dying phase and the quality of care of their relatives are relevant, as they need to live on with memories.

What this paper adds

- This study shows that from 2005 to 2019, family caregivers increasingly appreciated the quality of care provided to their relative with dementia dying in a nursing home. -Family caregivers' evaluation of quality of dying, however, did not improve, indicating that families did not perceive fewer symptoms over time, and even perceived lower well-being while dying (items on serenity, peace, and calm).

Implications for practice, theory or policy

- Monitoring trends in the palliative care for people with dementia may aid our understanding of the influence of policy and societal developments.
- Research is needed to explain trends and help to decrease symptom burden and improve quality of dying for people with dementia.

Introduction

In Western European countries such as the UK and the Netherlands, most people with dementia eventually move to a nursing home, where they reside until death.¹⁻³ Nursing home residents may benefit from palliative care with a focus on comfort and quality of life.^{4,5} The cognitive impairment associated with moderate or advanced dementia often leads to limited verbal expression of needs. This complicates the assessment of specific palliative care needs and addressing of symptoms.^{6,7} Family caregivers of people with dementia fulfill important roles as spokespersons, care partners, informants and proxy decision-makers.⁸⁻¹¹ Their role continues after nursing home admission.^{12,13} Staff should acknowledge the family caregivers' role in the care for people with dementia, especially at the end of life.¹⁴⁻¹⁶ Families' experiences with end-of-life care and their interactions with professional caregivers potentially influence their post-bereavement outcomes.¹⁷ "How people die remains in the memories of those who live on" is a famous quote in palliative care literature.¹⁸ Memories of family members reflect the dying experience and may expose specific points for improvement in end-of-life care.¹⁹ Family caregivers are important judges of the quality of end-of-life care provided to residents with dementia and of their quality of dying.^{20,21} Validated instruments are available to measure quality of care and quality of dying from the family perspective.^{22,23} A small study that investigated data from 2005 to 2010 showed a positive trend in families' reports of quality of end-of-life care for nursing home residents with dementia.²⁴ Exploring such trends can aid our understanding of how the experiences of family caregivers with end-of-life care may have changed, which informs future initiatives to improve palliative and end-of-life care. The present study examines trends in quality of care and quality of dying up to 2019 as judged by family caregivers of residents with dementia in Dutch nursing homes. Various national initiatives aimed to improve knowledge on palliative care in the Netherlands over the last decade. Therefore, the hypothesis is that these trends over a period in which development of dementia palliative care continued, are positive.

Methods

Study population

Data from eight studies conducted in the Netherlands in overlapping time windows between 2005 and 2019 were combined for trend analyses (Table 1).^{22,24-30} For seven of the studies, it concerned a secondary analysis of data collected to address various research questions (Supplement). The main goal of the eighth and most recent study was to enhance assessment of trends over time. Some studies employed nationally representative sampling, whereas other studies were regional. All studies collected data retrospectively, and one study also collected data prospectively (Table 1).^{22,24-30} Data collected during any intervention condition were excluded. The data concern 1189 persons with dementia who died in 117 nursing home facilities. One facility contributed to two studies (studies 1 and 3, Table 1). The family caregivers who were the primary contact persons were

invited to complete a questionnaire; within 1.5 to 2 months after death in most studies, and up to about a year after death in two studies (studies 6 and 8, Table 1). All nursing home residents included in these studies received medical care by a certified elderly care physician.³¹

Instruments

Quality of end-of-life care was measured with the End-of-Life in Dementia Satisfaction With Care (EOLD-SWC) instrument.^{20, 23} It has the most favourable psychometric properties as compared to other such instruments and it comprises 10 items regarding experiences on quality of care from the perspective of the family caregiver.²² The items cover decision-making, communication, understanding the resident's condition and medical care. The response options are: strongly disagree, disagree, agree, and strongly agree. Three items are negatively phrased statements, which require reverse coding before summing to total scores that range from 10 to 40. A higher score indicates better quality of end-of-life care.

The End-of-Life in Dementia Comfort Assessment in Dying (EOLD-CAD)²⁰ was used to measure quality of dying.^{23, 32} The EOLD-CAD comprises 14 items on symptoms such as pain, shortness of breath, choking, and fear. It also includes three positive items in a 'Well being' subscale. This subscale consists of items serenity, peace and calm, which require reverse coding. The three response options are: a lot, somewhat and not at all. Total scores range from 14 to 42, a higher score indicating a better perceived quality of dying. Most studies (6 out of 8) referred to the last week of life. One study used a skip pattern for the EOLD-CAD if the relative was not present during dying, setting a higher bar with regard to actual presence to observe comfort. (Table 1)

Cognition

All residents had a physician's diagnosis of dementia and resided in a psychogeriatric unit. Studies 1, 2, 3 and 5 (Table 1) included staff assessment using the Bedford Alzheimer Nursing Severity-Scale (BANS-S) to measure the severity of the dementia in the months before death. BANS-S scores range from 7 to 28. A score of 17 or higher represents severe dementia.^{33, 34} In studies 1 to 5, staff assessed whether residents were fully dependent in eating. Full eating dependence indicates very severe cognitive impairment and is equal to the highest level of impairment on the Cognitive Performance Scale (CPS 6).^{35, 36}

Trend analysis

The EOLD-SWC and EOLD-CAD scores in the combined dataset were analysed with mixed models, using time of death relative to the first death in the first study as the independent variable. The models included random effects for season (as seasonality in cause of death might vary between years) and for clustering of residents within nursing homes.^{37, 38} In study 7, only the month of death was available due to privacy regulations, and we imputed the 14th for February and the 15th for other months. We provide 95% confidence intervals around the estimate for time. Models were adjusted for characteristics of residents (age and gender), and family caregivers (gender, relationship to resident), region (urbanised Western and central region

Table 1 Overview of datasets combined for trend analyses on quality of care and quality of dying

Study	Main reference for study/ included in early combined analyses	Period	Design	Number of nursing homes, area in Netherlands
1. Gijsberts et al.	Ned Tijdschr Geneesk ²⁴ Palliat Med ²⁵ Int Psychogeriatr ²⁶	Sept 2005- june 2007	Retrospective, observational	4 facilities, West/Central
2. Van Soest-Poortvliet et al. Psychometric instrument study	Ned Tijdschr Geneesk ²⁴ JAMDA ²²	Feb 2008-April 2009	Retrospective, observational	14 facilities, West/Central
3. DEOLD Study	Ned Tijdschr Geneesk ²⁴ ADAD ²⁷	Feb 2007- July 2010	Prospective and retrospective, observational	40* facilities of 17 health care organisations, nationwide
4. FOLLow-Up Study	Palliat Med ²⁸	Jan 2012- June 2014	Retrospective, cluster RCT	18# facilities, nationwide
5. PACE, European study	JAMDA ^{29 30}	Dec 2014- Nov 2015	Retrospective, 6 countries also non-dementia, observational	25 facilities, stratified sampling, nationwide
6. Proeftuin Dementie	No publication yet	Feb 2017- Oct 2017	Retrospective, observational (intervention not implemented in nursing homes)	4 facilities of 1 health care organization, North of NL
7. DEDICATED (Desired Dementia Care Towards End of Life)	No publication yet	Feb 2018- Sept 2019	Retrospective, observational	7 facilities of 1 health care organization, South of NL
8. Marente, New data collection	No publication yet	April 2018- Dec 2018	Retrospective, observational	6 facilities of 1 health care organization, West of NL

EOLD-SWC=End-of-Life in Dementia-Satisfaction with Care, EOLD-CAD= End-of-Life in Dementia-Comfort Assessment in Dying, DEOLD=Dutch End Of Life in Dementia, FOLLow-up=Feedback on End-of_Life care in dementia, PACE=Palliative Care in care Homes Across Europe,

Number of residents with dementia (response rate)	Time questionnaire sent to family caregiver after death	Study aim	Timeframe, last:	
			EOLD-SWC	EOLD-CAD
54 (61%)	2 months	Validate Dutch translation. Compare anthroposophical nursing homes to nursing homes without affiliation. Comparison of after-death scores of family caregivers and nurses, and of Dutch and US family caregivers.	Last 90 days	During his/her dying
70 (59%)	2 months	Assess psychometric properties of instruments to evaluate quality of care and death in long-term care	Last month	Last week
248 (58%)	6 weeks	Asses factors associated with quality of care and quality of dying	Last week	During his/her dying, only if present
537 (65%)	6 weeks	Assessment of effect of feedback strategies in perceived end of life care and comfort	Last month	Last week
89 (62%)	2 to 4 months	Comparison of palliative care in nursing homes in 6 European countries	Last week	Last week
16 (43%)	6 to 13 months	Improving palliative care with mobile palliative care teams	Last week	Last week
125 (62%)	6 to 8 weeks	Improving palliative care for people with dementia and caregivers	Last 3 months	Last week
50 (58%)	3 to 12 months	Additional data to address research question of possible trend in evaluation end of life care	Last week	Last week

DEDICATED=Desired Dementia Care Towards End of Life, *=included nursing homes after move, #=only pre-test and control group in trend analysis

of the country with greater staffing problems versus other region), and design (prospective enrolment of residents versus retrospectively after death). We conducted sensitivity analyses with additional adjustment for severity of dementia measured with the BANS-S or the eating dependence item (CPS 6) and family caregiver's age. We also added a quadratic term for time to assess the fit of a non-linear model. Descriptive statistics were used for respondent characteristics. If less than one third of EOLD items missed, the items were imputed with the patient item mean to generate a total score. All analyses were performed in SPSS Inc, version 25, 2017, IBM, USA.

Results

The mean age of the residents was 85.5 years; 67.9% were female (Table 2). A little over half (53.7%) had severe dementia and almost a third (29.4%) were fully dependent in eating (no data available for the studies covering 2018 and 2019). Distributions of age, gender and dementia severity were fairly homogeneous between the eight studies (Table 2). Of the family caregivers, the majority were female (62.8%), and most were sons or daughters (in-law) of the resident (65.8%). The EOLD-SWC (quality of care) mean total ranged from 31.9 to 34.1, and the EOLD-CAD (quality of dying) mean total score ranged from 27.2 to 33.3 across studies (Table 3). The correlation between the EOLD-SWC and the EOLD-CAD for quality of dying was weak (+0.27, $P < 0.001$). Figure 1a shows unadjusted quality of care means per 2 years; the curve is steeper in earlier years and flattens over time when variable error bars are taken into consideration. The EOLD-SWC total score significantly increased by 0.148 points per year (CI, 0.052 to 0.244), and in the adjusted model the trend was an additional 0.170 points per year (CI, 0.055 to 0.285) (Table 4). The EOLD-CAD total score significantly decreased by -0.175 points per year (CI, -0.291 to -0.058; Table 4 and Figure 1b) but in the adjusted model the trend was not significant with a decrease of -0.070 points per year (CI, -0.205 to 0.065). The difference of EOLD-CAD with the adjusted model (-0.070 versus -0.175 unadjusted; Table 4) was driven by adjustment for prospective versus retrospective design. The subscale 'Well Being' significantly decreased by -0.076 points per year (CI, -0.114 to -0.039) in the unadjusted model, and in the adjusted model by -0.073 points per year (CI, -0.119 to -0.028). The other subscale scores showed no significant trend. Trend models in EOLD-SWC and EOLD-CAD for separate studies are shown in Supplementary figures 1 and 2. The sensitivity analyses showed similar estimates. A quadratic term for time was significant for the EOLD-SWC in both the unadjusted ($P = 0.002$) and the adjusted model ($P < 0.001$; Supplementary figure 3). A quadratic term for change over time was not significant in the unadjusted model for EOLD-CAD ($P = 0.096$) or the adjusted model ($P = 0.223$).

Figure 1a EOLD-SWC means per 2-year intervals with 95% CI bars

EOLD-SWC=End-of-Life in Dementia-Satisfaction with Care, CI=Confidence Interval

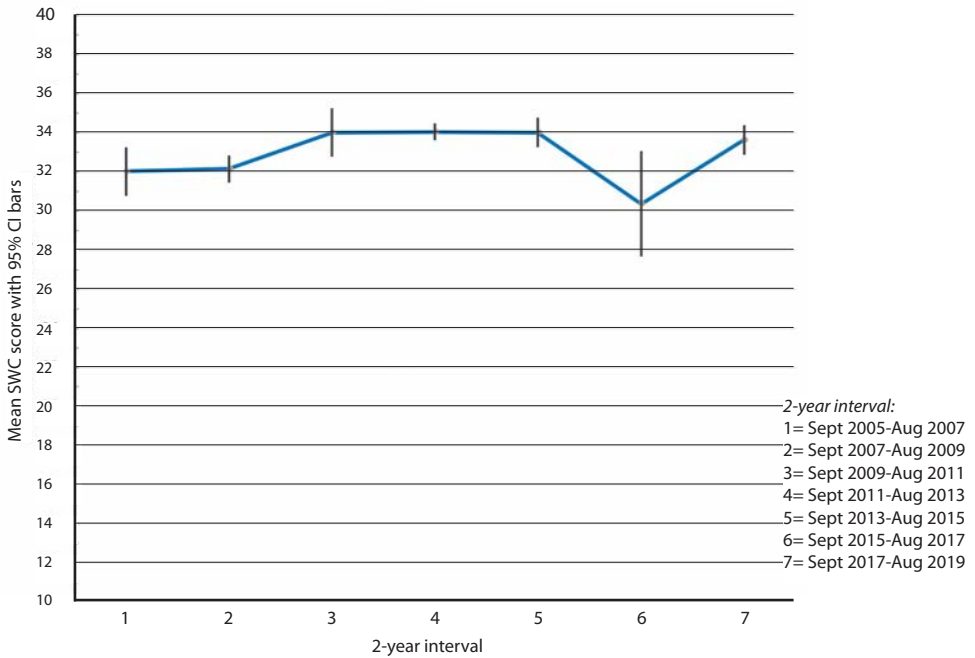


Figure 1b EOLD-CAD means per 2-year intervals with 95% CI bars

EOLD-CAD= End-of-Life in Dementia-Comfort Assessment in Dying, CI=Confidence Interval

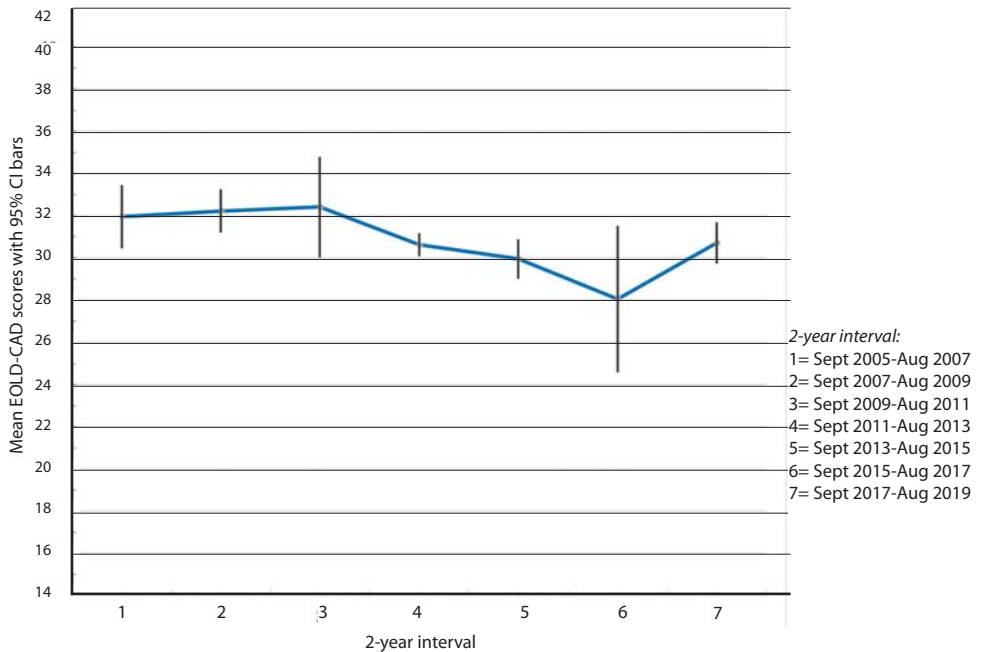


Table 2 Characteristics of nursing home residents who died with dementia and their relatives

Mean (SD) or %, [n]	Total all studies	Gijsberts	Van Soest	DEOLD
Number of residents	1189	54	70	248
Age, mean number of years; (SD) [n]	85.5 (7.6) [1178/1189]	85.1 (5.8) [54/54]	88.8 (5.9) [67/70]	85.6 (7.1) [244/248]
Female, % [n]	67.9 [807/1189]	80 [43/54]	89 [62/70]	67 [165/248]
Severity of dementia, BANS-S mean score, (SD), [n]	17.1 (4.0) [428/461]	18.6 (3.3) [54/54]	17.9 (4.2) [70/70]	16.3 (3.7) [248/248]
Severe dementia, BANS-S score 17 or higher % [n]	53.7 [230/428]	83 [45/54]	73 [51/70]	41 [102/248]
Full eating dependency (CPS 6), % [n]	29.4 [271/923]	33 [16/48]	38 [21/54]	26 [61/237]
Caregiver female, % [n]	62.8 [747/1186]	61 [33/54]	67 [47/70]	61 [151/246]
Age caregiver, mean number of years (SD) [n]	62.0 (11.2) [1126]	Not available	60.6 (8.5) [70/70]	60.6 (11.2) [246/248]
Relationship caregiver, % [n]				
-spouse	18.5 [220]	12 [6]	6 [4]	19 [46]
-child	65.8 [782]	71 [37]	87 [61]	66 [161]
-other	15.3 [181]	17 [9]	7 [5]	16 [38]

SD=standard deviation, BANS-S=Bedford Alzheimer Nursing Severity-Scale

Table 3 Total scores for quality of care (EOLD-SWC; n=1169) and quality of dying (EOLD-CAD; n= 903) across studies

Study/ project, mean (SD)	EOLD-SWC	n/total n	EOLD-CAD	n/total n
1. Gijsberts	31.9 (4.7)	54/54	32.0 (5.4)	52/54
2. Van Soest-Poortvliet	32.1 (5.8)	68/70	30.7 (5.3)	59/70
3. DEOLD	32.6 (5.3)	242/248	33.3 (5.9)	88/90
4. FOLlow-up	34.1 (4.8)	535/537	30.6 (5.6)	466/537
5. PACE	33.8 (5.2)	86/89	29.7 (5.6)	80/89
6. Proeftuin Dementie	30.2 (6.3)	16/16	27.2 (7.2)	13/16
7. DEDICATED	33.7 (5.0)	118/125	30.6 (6.2)	101/125
8. Marente	33.4 (4.8)	50/50	30.8 (5.5)	44/50

EOLD-SWC=End-of-Life in Dementia-Satisfaction with Care, EOLD-CAD= End-of-Life in Dementia-Comfort Assessment in Dying

FOLlow-up	PACE	Proeftuin Dementie	DEDICATED	Marente
537	89	16	125	50
84.9 (8.1)	85.6 (7.2)	85.4 (7.5)	85.7 (7.7)	85.5 (7.0)
[535/537]	[89/89]	[15/16]	[125/125]	[49/50]
68	60	50	60	72
[366/537]	[53/89]	[8/16]	[74/125]	[36/50]
Not available	17.9 (4.9) [56/89]	Not available	Not available	Not available
Not available	57 [32/56]	Not available	Not available	Not available
29	33	Not available	Not available	Not available
[155/529]	[18/55]			
62	68	63	61	78
[331/537]	[60/88]	[10/16]	[76/125]	[39/50]
62.7 (11.8)	63.4 (11.0)	65.3 (9.8)	62.4 (10.5)	59.8 (9.6)
[533/537]	[88/89]	[16/16]	[123/125]	[50/50]
21 [113]	23 [20]	19 [3]	18 [22]	12 [6]
63 [338]	60 [53]	50 [8]	70 [87]	74 [37]
16 [86]	18 [16]	31 [5]	12 [15]	14 [7]

CPS=Minimum Data Set Cognitive Performance Scale

Table 4 Trends in total and item quality of care scores (EOLD-SWC) and in total and subscale quality of dying scores (EOLD-CAD)

	Mean (SD) [n]	Trend; coefficient (95%-CI) unadjusted	Trend; coefficient (95%-CI) adjusted
EOLD-SWC total^a	33.40 (5.08) [1169]	0.148 (0.052 to 0.244)	0.170 (0.055 to 0.285)
a. I felt fully involved in all decision making	3.41 (0.66) [1171]	0.017 (0.005 to 0.029)	0.017 (0.002 to 0.032)
b. I would probably have made different decisions if I had had more information	3.30 (0.73) [1137]	0.006 (-0.008 to 0.019)	0.011 (-0.006 to 0.027)
c. All measures were taken to keep my relative comfortable	3.47 (0.66) [1167]	0.024 (0.012 to 0.037)	0.030 (0.016 to 0.045)
d. The health care team were sensitive to my needs and feelings	3.35 (0.65) [1146]	0.019 (0.007 to 0.031)	0.015 (0.001 to 0.030)
e. I did not really understand my relative's condition	3.35 (0.78) [1150]	0.011 (-0.002 to 0.024)	0.010 (-0.005 to 0.026)
f. I always knew which doctor or nurse was in charge of my relative's care	3.03 (0.78) [1165]	0.014 (-0.000 to 0.029)	0.011 (-0.006 to 0.029)
g. I felt that my relative got all necessary nursing assistance	3.42 (0.66) [1170]	0.019 (0.007 to 0.031)	0.026 (0.011 to 0.040)
h. I felt that all medication issues were clearly explained to me	3.27 (0.71) [1155]	0.016 (0.004 to 0.029)	0.021 (0.005 to 0.036)
i. My relative was receiving all treatments or interventions that he or she could benefit from	3.38 (0.66) [1164]	0.015 (0.004 to 0.027)	0.016 (0.002 to 0.030)
j. I feel that my relative needed better medical care at the end of his or her life	3.42 (0.76) [1159]	0.005 (-0.008 to 0.019)	0.010 (-0.006 to 0.026)
EOLD-CAD total^b	30.80 (5.76) [903]	-0.175 (-0.291 to -0.058)	-0.070 (-0.205 to 0.065)
1. Physical distress ^c (item 1, 2, 3, 4, score range 4-12)	8.34 (2.09) [935]	-0.037 (-0.079 to 0.004)	0.00001 (-0.048 to 0.048)
2. Dying symptoms ^d (item 4 (part of two subscales), 5, 6, 7, score range 4-12)	8.85 (2.20) [922]	-0.017 (-0.059 to 0.025)	0.017 (-0.032 to 0.067)
3. Emotional distress ^e (item 8, 9, 10, 11, score range 4-12)	9.54 (2.19) [904]	-0.061 (-0.104 to -0.019)	-0.026 (-0.077 to 0.025)
4. Well being ^f (item 12, 13, 14, score range 3-9)	6.14 (1.98) [908]	-0.076 (-0.114 to -0.039)	-0.073 (-0.119 to -0.028)

EOLD-SWC=End-of-Life in Dementia-Satisfaction with Care, EOLD-CAD= End-of-Life in Dementia-Comfort Assessment in Dying, SD=standard deviation, CI=confidence interval, **italics and bold**= $p < 0.05$, EOLD-SWC item scores are presented because the total score trend is significant

Cronbach's α : ^a= EOLD-SWC total: 0.90, ^b= EOLD-CAD total: 0.83, ^c= EOLD-CAD subscale Physical distress: 0.62, ^d= EOLD-CAD subscale Dying symptoms: 0.68, ^e= EOLD-CAD subscale Emotional distress: 0.78, ^f= EOLD-CAD subscale Well being: 0.91

Discussion

Main findings

This study investigated trends in family caregivers' assessments of quality of end-of-life care and quality of dying of nursing home residents with dementia in the Netherlands. From 2005 to 2019, quality of care improved, in particular in the earlier years. Quality of dying did not significantly change in adjusted analyses that included adjustment for prospective design, but scores on the subscale 'Well being' nevertheless decreased, also after adjustment.

The statistically significant changes are relevant long-term changes as they may represent ongoing change, and a 2.4 increase in EOLD-SWC total score, for example, nears 3 used in power calculations.³⁹ The progressive and terminal nature of dementia and the complex care needs that accompany dementia underpin a palliative approach to care.^{5,40} The evidence-base for palliative dementia care is still small but will expand over the coming years.⁴¹ The early increase in quality of care in the Netherlands may be related to political developments in palliative care from the late 1990s onward.⁴² A 1997 policy programme aimed to integrate palliative care into the regular healthcare system, to increase practitioners' skills and knowledge.⁴³ In Dutch national dementia plans, however, palliative or end-of-life care is not mentioned.⁴⁴ Treatments for symptom relief in nursing home residents with dementia increased in 2006-2007 compared to the late 1990s.⁴⁵ Reasons for this increase, according to physicians, included growing attention and awareness regarding symptom relief, clearer treatment goals and a focus on quality of life.⁴⁵ Palliative care specialists are consulted for residents in Dutch nursing homes with dementia, in only 2.5% of the cases.⁴⁶ Compared to five other European countries, however, the treating physician in Dutch nursing homes is involved in palliative care more often (in 98.8% of the cases).^{30,47}

In the context of increasing quality of end-of-life care as perceived by family and increasing awareness regarding palliative care as perceived by physicians⁴⁵, finding no improvement on the quality of dying scale and a decline on the 'Well being' subscale is counterintuitive. Further, scores on the quality of care items, regarding measures taken to improve comfort and regarding nursing assistance showed the highest increase. Other studies also found weak to moderate associations between quality of care evaluated by families and perceived quality of dying.^{48,49} An interesting artefact may have been introduced by a design issue, with a negative trend for a prospective design (Supplement figures 1 and 2). Repeated completion of questionnaires on symptom burden in the prospective study may also have increased family caregivers' awareness of symptoms in the dying phase. These family caregivers may have been prompted to report more symptoms. Nevertheless, controlled for design, the trend was also negative for the subscale 'Well Being' that comprises the items 'serenity', 'peace' and 'calm'. Family caregivers may hold negative perceptions about the end of life with dementia as being undignified, especially in Western societies where autonomy is highly valued.⁵⁰ Increasing media exposure and public campaigns on 'living well with dementia', in combination with

the Dutch debate on the acceptability of euthanasia in dementia in recent years might influence such perceptions. Lemos Dekker found that family caregivers of nursing home residents with dementia may feel powerless due to a lack of control over relief of their relatives' suffering.⁵⁰ Higher expectations and standards of care, and increased focus on control and dignity might explain a decrease in their assessment of well-being in dying, while their assessment of concrete symptoms remained unchanged. Future research is needed to disentangle what well-being in dying means to families.

Strengths and limitations

This study used perspectives from more than one thousand family caregivers of nursing home residents with dementia, over a period of 14 years. It does not evaluate a single reform as there were various initiatives to improve palliative care. Identifying of individual items that did or did not change further enhances the study's relevance to clinical practice. The EOLD-SWC has strong psychometric properties, whereas there is some ambiguity about the psychometric properties of the EOLD-CAD regarding feasibility, validity and reliability.^{22,51} Although the EOLD-CAD items all assess aspects of quality of dying, the instrument does not cover the full concept of quality of dying, which may include aspects that are more difficult to assess such as retaining identity or dignity.⁵² Nonetheless, other such measures do not perform better or properties are unknown. The EOLD-SWC and EOLD-CAD scales have been widely used after an early comparison of psychometric properties,²² which facilitates comparison between countries.^{30,53} This study was limited to the Netherlands, but its EOLD scores are fairly representative for recent European research.³⁰ Sample sizes, recruitment methods and the period before death referred to in the EOLD instruments varied between the individual studies in the analyses. There may be residual confounding by unmeasured confounders. However, any confounding by dementia severity is unlikely as adjusted estimates were unchanged in sensitivity analyses.

Conclusion

This study observed a positive trend in family caregivers' assessments of the quality of end-of-life care for nursing home residents with dementia over a period of 14 years. Family caregivers' assessments of quality of dying did not change with regard to symptoms during dying, but according to their assessments the well-being during dying decreased over time. There may be a growing gap between family caregivers' expectations and actual symptoms and well-being at the end of life. These observations call for further monitoring of quality perceived by family and research to investigate contemporary ideas about what constitutes a 'good and comfortable death' at the end of life with dementia.

Author contribution

MK, WA and JvdS developed the original concept for this study. MK and JvdS analysed the data. BM advised on the statistical analysis. MK, SB and JvdS wrote the manuscript, and all authors reviewed and commented on the subsequent drafts. All authors read and approved the final manuscript.

Declaration of conflicting interest

The author(s) declared the following potential conflicts of interest with respect to the research, authorship, and/or publication of this article: All authors have completed the ICMJE uniform disclosure form at www.icmje.org/coi_disclosure.pdf and declare: no support from any organization for the submitted work; no financial relationships with any organizations that might have an interest in the submitted work in the previous three years; no other relationships or activities that could appear to have influenced the submitted work.

Funding

No external funding

Data availability statement

The data sets generated and analyzed during the current study are not publicly available. The combined data are available upon reasonable request and permission granted from the owners of all datasets.

Supplemental material

Supplemental material for this article is available online.

Reference list

1. Honinx E, van Dop N, Smets T, et al. Dying in long-term care facilities in Europe: the PACE epidemiological study of deceased residents in six countries. *BMC public health*. 2019; 19: 1199.
2. Reyniers T, Deliëns L, Pasman HR, et al. International variation in place of death of older people who died from dementia in 14 European and non-European countries. *Journal of the American Medical Directors Association*. 2015; 16: 165-71.
3. Joling KJ, Janssen O, Francke AL, et al. Time from diagnosis to institutionalization and death in people with dementia. *Alzheimer's & dementia : the journal of the Alzheimer's Association*. 2020; 16: 662-71.
4. Froggatt K, Payne S, Morbey H, et al. Palliative Care Development in European Care Homes and Nursing Homes: Application of a Typology of Implementation. *Journal of the American Medical Directors Association*. 2017; 18: 550.e7-.e14.
5. van der Steen JT, Radbruch L, Hertogh CM, et al. White paper defining optimal palliative care in older people with dementia: a Delphi study and recommendations from the European Association for Palliative Care. *Palliative medicine*. 2014; 28: 197-209.
6. Erel M, Marcus EL and Dekeyser-Ganz F. Barriers to palliative care for advanced dementia: a scoping review. *Annals of palliative medicine*. 2017; 6: 365-79.
7. Blackstone KA and Cobbs EL. Palliative care for persons with dementia. *Journal of the American Geriatrics Society*. 2021.
8. Graneheim UH, Johansson A and Lindgren BM. Family caregivers' experiences of relinquishing the care of a person with dementia to a nursing home: insights from a meta-ethnographic study. *Scandinavian journal of caring sciences*. 2014; 28: 215-24.
9. Bern-Klug M and Forbes-Thompson S. Family members' responsibilities to nursing home residents: "she is the only mother I got". *Journal of gerontological nursing*. 2008; 34: 43-52.
10. Lord K, Livingston G and Cooper C. A systematic review of barriers and facilitators to and interventions for proxy decision-making by family carers of people with dementia. *International psychogeriatrics / IPA*. 2015; 27: 1301-12.
11. Givens JL, Kiely DK, Carey K and Mitchell SL. Healthcare proxies of nursing home residents with advanced dementia: decisions they confront and their satisfaction with decision-making. *Journal of the American Geriatrics Society*. 2009; 57: 1149-55.
12. Brodaty H and Donkin M. Family caregivers of people with dementia. *Dialogues in clinical neuroscience*. 2009; 11: 217-28.
13. Ross MM, Carswell A and Dalziel WB. Family caregiving in long-term care facilities. *Clinical nursing research*. 2001; 10: 347-63; discussion 64-8.
14. Boogaard JA, van der Steen JT, de Boer AH and van Groenou MIB. How Is End-of-Life Care With and Without Dementia Associated With Informal Caregivers' Outcomes? *The American journal of hospice & palliative care*. 2019; 36: 1008-15.
15. Bolt S, van der Steen J, Schols J, Zwakhalen S and Meijers J. What do relatives value most in end-of-life care for people with dementia? *International journal of palliative nursing*. 2019; 25: 432-42.

16. Reid RC and Chappell NL. Family Involvement in Nursing Homes: Are Family Caregivers Getting What They Want? *Journal of applied gerontology : the official journal of the Southern Gerontological Society*. 2017; 36: 993-1015.
17. Shuter P, Beattie E and Edwards H. An Exploratory Study of Grief and Health-Related Quality of Life for Caregivers of People With Dementia. *American journal of Alzheimer's disease and other dementias*. 2014; 29: 379-85.
18. Saunders. Pain and impending death. *Textbook of Pain* New York, NY: Churchill Livingstone. 1984; pp. 472–8.
19. Teno JM, Clarridge BR, Casey V, et al. Family perspectives on end-of-life care at the last place of care. *Jama*. 2004; 291: 88-93.
20. Volicer L, Hurley AC and Blasi ZV. Scales for evaluation of End-of-Life Care in Dementia. *Alzheimer disease and associated disorders*. 2001; 15: 194-200.
21. McPherson CJ and Addington-Hall JM. Judging the quality of care at the end of life: can proxies provide reliable information? *Social science & medicine* (1982). 2003; 56: 95-109.
22. van Soest-Poortvliet MC, van der Steen JT, Zimmerman S, et al. Selecting the best instruments to measure quality of end-of-life care and quality of dying in long term care. *Journal of the American Medical Directors Association*. 2013; 14: 179-86.
23. van Soest-Poortvliet MC, van der Steen JT, Zimmerman S, et al. Psychometric properties of instruments to measure the quality of end-of-life care and dying for long-term care residents with dementia. *Quality of life research : an international journal of quality of life aspects of treatment, care and rehabilitation*. 2012; 21: 671-84.
24. van der Steen JT, van Soest-Poortvliet MC, Gijsberts MJ, et al. [Improved end-of-life care for patients with dementia: greater family satisfaction and possibly greater end-of-life comfort]. *Nederlands tijdschrift voor geneeskunde*. 2013; 157: A5324.
25. van der Steen JT, Gijsberts MJ, Knol DL, Deliëns L and Muller MT. Ratings of symptoms and comfort in dementia patients at the end of life: comparison of nurses and families. *Palliative medicine*. 2009; 23: 317-24.
26. van der Steen JT, Gijsberts MJ, Muller MT, Deliëns L and Volicer L. Evaluations of end of life with dementia by families in Dutch and U.S. nursing homes. *International psychogeriatrics / IPA*. 2009; 21: 321-9.
27. van der Steen JT, Ribbe MW, Deliëns L, Gutschow G and Onwuteaka-Philipsen BD. Retrospective and prospective data collection compared in the Dutch End Of Life in Dementia (DEOLD) study. *Alzheimer disease and associated disorders*. 2014; 28: 88-94.
28. Boogaard JA, de Vet HC, van Soest-Poortvliet MC, Anema JR, Achterberg WP and van der Steen JT. Effects of two feedback interventions on end-of-life outcomes in nursing home residents with dementia: A cluster-randomized controlled three-armed trial. *Palliative medicine*. 2018; 32: 693-702.
29. Van den Block L, Smets T, van Dop N, et al. Comparing Palliative Care in Care Homes Across Europe (PACE): Protocol of a Cross-sectional Study of Deceased Residents in 6 EU Countries. *Journal of the American Medical Directors Association*. 2016; 17: 566.e1-7.
30. Pivodic L, Smets T, Van den Noortgate N, et al. Quality of dying and quality of end-of-life care of nursing home residents in six countries: An epidemiological study. *Palliative medicine*. 2018: 269216318800610.

31. Koopmans RT, Lavrijsen JC, Hoek JF, Went PB and Schols JM. Dutch elderly care physician: a new generation of nursing home physician specialists. *Journal of the American Geriatrics Society*. 2010; 58: 1807-9.
32. Stewart AL, Teno J, Patrick DL and Lynn J. The concept of quality of life of dying persons in the context of health care. *Journal of pain and symptom management*. 1999; 17: 93-108.
33. Appollonio I, Gori C, Riva G, et al. Assessing early to late stage dementia: the TSI and BANS-S scales in the nursing-home. *International journal of geriatric psychiatry*. 2005; 20: 1138-45.
34. Volicer L, Hurley AC, Lathi DC and Kowall NW. Measurement of severity in advanced Alzheimer's disease. *Journal of gerontology*. 1994; 49: M223-6.
35. Morris JN, Fries BE, Mehr DR, et al. MDS Cognitive Performance Scale. *Journal of gerontology*. 1994; 49: M174-82.
36. van der Steen JT, Volicer L, Gerritsen DL, Kruse RL, Ribbe MW and Mehr DR. Defining severe dementia with the Minimum Data Set. *International journal of geriatric psychiatry*. 2006; 21: 1099-106.
37. Fitzmaurice GM, Laird, NM, Ware, JM. *Applied Longitudinal Analysis*. 2012.
38. Molenberghs G, Verbeke, G. A review on linear mixed models for longitudinal data, possibly subject to dropout. *Statistical Modelling*. 2001; Volume: 1 page(s): 235-69.
39. Boogaard JA, van Soest-Poortvliet MC, Anema JR, et al. Feedback on end-of-life care in dementia: the study protocol of the FOLlow-up project. *BMC palliative care*. 2013; 12: 29.
40. van der Steen JT, Lemos Dekker N, Gijsberts MHE, Vermeulen LH, Mahler MM and The BA. Palliative care for people with dementia in the terminal phase: a mixed-methods qualitative study to inform service development. *BMC palliative care*. 2017; 16: 28.
41. Murphy E, Froggatt K, Connolly S, et al. Palliative care interventions in advanced dementia. *The Cochrane database of systematic reviews*. 2016; 12: Cd011513.
42. Soest v. De organisatie van de palliatieve zorg in Nederland. In: Berendsen A., van Soest F. (eds) *Inzichten in de palliatieve zorg*. Bohn Stafleu van Loghum, Houten. https://doi.org/10.1007/978-90-368-0826-2_1. 2014: pp 3-14.
43. Francke AL and Kerkstra A. Palliative care services in The Netherlands: a descriptive study. *Patient education and counseling*. 2000; 41: 23-33.
44. Nakanishi M and van der Steen JT. National dementia plans to address escalating global palliative care needs. *Palliative medicine*. 2020; 34: 966-7.
45. van der Steen JT, Meuleman-Peperkamp I and Ribbe MW. Trends in treatment of pneumonia among Dutch nursing home patients with dementia. *Journal of palliative medicine*. 2009; 12: 789-95.
46. van der Steen JT, Deliens L, Koopmans R and Onwuteaka-Philipsen BD. Physicians' perceptions of suffering in people with dementia at the end of life. *Palliative & supportive care*. 2017; 15: 587-99.
47. Ten Koppel M, Onwuteaka-Philipsen BD, Van den Block L, et al. Palliative care provision in long-term care facilities differs across Europe: Results of a cross-sectional study in six European countries (PACE). *Palliative medicine*. 2019: 269216319861229.
48. Liu LM, Guarino AJ and Lopez RP. Family satisfaction with care provided by nurse practitioners to nursing home residents with dementia at the end of life. *Clinical nursing research*. 2012; 21: 350-67.

49. Engel SE, Kiely DK and Mitchell SL. Satisfaction with end-of-life care for nursing home residents with advanced dementia. *Journal of the American Geriatrics Society*. 2006; 54: 1567-72.
50. Lemos Dekker N. Moral frames for lives worth living: Managing the end of life with dementia. *Death studies*. 2017: 1-7.
51. Kupeli N, Candy B, Tamura-Rose G, et al. Tools Measuring Quality of Death, Dying, and Care, Completed after Death: Systematic Review of Psychometric Properties. *The patient*. 2018.
52. Nishimura M, Denning, K.H., Sampson, E.L., Vidal, E.I.O., Abreu, W.C., Kaasalainen, S., Eisenmann, Y., Dempsey, L., Moore, K.J., Davies, N., Bolt, S.R., Meijers J.M.M., Lemos Dekker, N., Miyashita, M., Nakanishi, M., Nakayama, T., & van der Steen, J.T. Cross-cultural conceptualisation of a good end of life with dementia: A meta-qualitative study. *The Alzheimer Disease International Conference 2020 Abstract book*. <https://www.alzint.org/u/ADI-2020-Abstract-Book.pdf> 2020: 64-5.
53. Cohen LW, van der Steen JT, Reed D, et al. Family perceptions of end-of-life care for long-term care residents with dementia: differences between the United States and the Netherlands. *Journal of the American Geriatrics Society*. 2012; 60: 316-22.

Supplement 1

Description of each study on inclusion of residents and study aims

*Study 1 Gijsberts et al.*¹⁻³

The 54 residents enrolled after death in this study were living in 4 nursing homes in the Western and central regions of the Netherlands. All deaths occurred between September 2005 and June 2007. The first study aim was to translate and validate the End of Life in dementia (EOLD) scales, the second aim was to compare anthroposophical nursing homes with nursing homes without religious or spiritual affiliation on quality of care, dying and symptom burden. The third aim was to compare after-death scores of family caregivers and nurses in the Netherlands and the US. Nurses identified family caregivers who had been most involved in the last months of life of residents diagnosed with dementia. An informed consent form was sent by postal mail 6 weeks after the death of their relative. After receiving consent, a printed questionnaire was mailed and was completed around 2 months after death. The response rate was 61%. The study protocol was approved in 2005 by the Medical Ethics Committee of VU University Medical Center in Amsterdam (number 05/098).

*Study 2 Psychometric instrument study, Van Soest-Poortvliet et al.*⁴

In this study, 70 residents were included after death. They had resided in 8 nursing homes and had been admitted at least 30 days before death between February 2008 and April 2009. This psychometric properties study was designed to test and compare all available instruments to measure quality of care and quality of death with dementia in long-term care. All residents had a physician's diagnosis of dementia and were admitted to a psychogeriatric unit (units with almost all patients having dementia) in nursing homes and residential homes. Informed consent was provided by family caregivers. The response rate was 59%. The Medical Ethical Committee of VU University Medical Center, Amsterdam, reviewed the protocol in 2008 as an extension of study 3. (number 06/179, 2006), and provided advice, declaring that the extension also did not fall under the Medical Research Involving Human Subjects Act (WMO).

*Study 3 DEOLD= Dutch End Of Life in Dementia, van der Steen et al.*¹⁵

The 491 residents in 19 nursing home organizations covering 34 facilities, enrolled in this study were included using a prospective design in 28 facilities (17 organizations) and a retrospective design in 6 other facilities (2 organizations, after-death questionnaires only). Family after-death questionnaires were returned for 183 residents who resided in the facilities involved in the prospective data collection, and 65 were returned for residents of facilities based on retrospective data collection only. Some residents moved and so the completed after-death questionnaires concerned 6 more facilities, resulting in a total of 40 facilities. Residents with completed after-death questionnaires died between February 2007 and July 2010. The main study aim was to assess factors

associated with quality of care and quality of dying. Other aims were to describe comfort, symptom burden, pain, decision making and treatment at the end of life. A total of 26 nursing home organizations were invited to participate, 17 agreed, representing a response rate of 65% (2 more nursing home organizations participated after taking the initiative and expressing an interest in participating). The family caregiver received a questionnaire around 2 months after the death of their relative. The response rate was 58%. The study protocol was judged not to fall under the scope of the Medical research Involving Human Subjects Act (WMO), as declared by the Medical Ethics Committee of VU University Medical Center in Amsterdam, in 2006 (*number 06/179 (2006)*).

*Study 4 FOLLOW-Up= Feedback on End-of-Life care in dementia*⁶

The 537 residents enrolled in this study all died on a psychogeriatric ward in 18 different nursing homes and were admitted at least 16 days in the last month of life. The time of death was between January 2012 and June 2014. The study aim was to assess the effect of (patient or generic) feedback strategy on perceived end-of-life care and comfort and the study design was a cluster-randomised 3-armed trial. For this trend analysis the residents who resided in the facilities assigned to the control condition (pre-intervention phase and intervention phase) and all residents who died in the pre-intervention period of the intervention groups (patient and generic feedback strategy) were included for analyses. Residents were included if they had stayed in the nursing home at least 16 days in the last month of life and had a dementia diagnosis in their medical file. Around 6 weeks after death the family care giver received an information letter and questionnaire, the response rate was 65%. This cluster-randomised controlled trial is registered in the Netherlands Trial Registration, NL3777 (NTR3942). The research protocol of the Follow-up study was reviewed by the Medical Ethics Review Committee of VU University Medical Center (number 2012/173; judged to not fall under the scope of the Medical research Involving Human Subjects Act (WMO)).

Study 5 PACE= Palliative Care in care Homes Across Europe^{7,8}

This study conducted in 6 countries included 329 people of whom 143 were residents of 25 nursing homes on a psychogeriatrics unit (mostly for people with dementia) at the time of death and 89 family caregivers returned the questionnaires, response rate 62%. These residents died between December 2014 to November 2015. The organizations were invited to participate through a random sampling procedure in each country, based on at least region/province and facility size (number of beds). The aim of the PACE study was to compare palliative care in nursing homes in 6 European countries. The study was funded in the European Commission FP7 program. Consent to participate was obtained when the questionnaire was returned. The Medical Ethics Review Committee of the VU University Medical Center Amsterdam provided a waiver from review as it was judged to not fall under the scope of the Medical Research Involving Human Subjects Act (WMO), 2015.

Study 6 Proeftuin Dementie

This study aimed at setting up palliative care team specialised in palliative care for people with dementia and evaluate its effects in 4 nursing homes. Family caregivers of nursing home residents completed questionnaires before the intervention was pilot tested, and the mobile team was consulted only for home-dwelling persons with dementia. The 16 residents with dementia included in this study (response rate 43%) had been admitted to a psychogeriatric ward of one of four nursing homes in the region where the study was conducted and died between February 2017 and September 2017. Relatives were contacted in March 2018 and asked to complete the questionnaire. Ethical review for the research protocol was provided by the Medical Ethics Review Committee of the Leiden University Medical Center (number P17.214; judged to not fall under the scope of the Medical research Involving Human Subjects Act (WMO)).

Studie 7 DEDICATED= Desired Dementia Care Towards End of Life

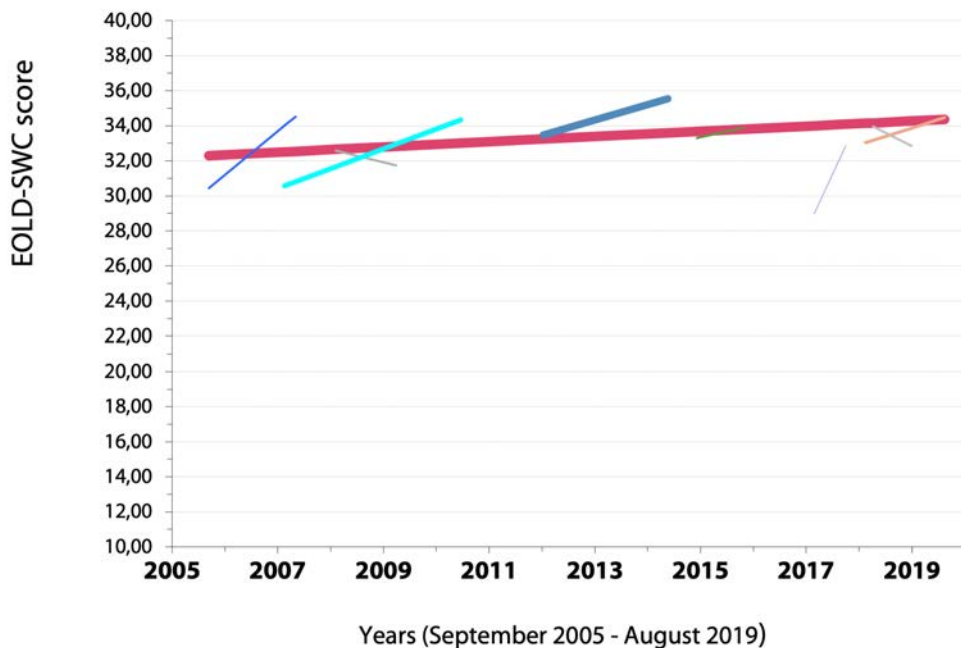
Between February 2018 and September 2019, 206 residents were included in this ongoing end-of-life study. The DEDICATED project aims to improve palliative care for people with dementia. The researchers collect quality of care and quality of dying data over time in one of the participating organizations. The current dataset includes 126 residents who resided on a psychogeriatric unit. For this analysis, we included 125 residents, excluding one resident with a missing date of death from the analysis. The family caregivers in this study received an information letter and questionnaire between 6 to 8 weeks after the residents' death, as part of the routine post-death assessment of the organization. The response rate was 61%. The study protocol was approved by the Medical Ethics Committee of the Maastricht University Medical Center (number METCZ20180026), judged to not fall under the scope of the Medical research Involving Human Subjects Act (WMO).

Study 8 Marente

This study was conceived for the purpose of addressing the research question about trends in family perspectives on quality of care and quality of dying. All caregivers who served as contact persons for staff received questionnaires if their family who resided on a psychogeriatric (mostly dementia) unit and died between first of March 2018 and 31st of December 2018 in one of six facilities of a care organization in the West of the Netherlands. The questionnaires were sent end of March 2019 to 86 relatives and 50 were returned between the first of April and 25th of May 2019, response rate 58%. We enquired with the Medical Ethics Review Committee of the Leiden University Medical Center; because of use of the same questionnaire as used in study 6, they regarded the ethics review for study 6 as leading and study 8 as an extension with more facilities of the observational part of study 6.

Supplement Figure 1 EOLD-SWC score unadjusted for covariates, with random effects for season and facility

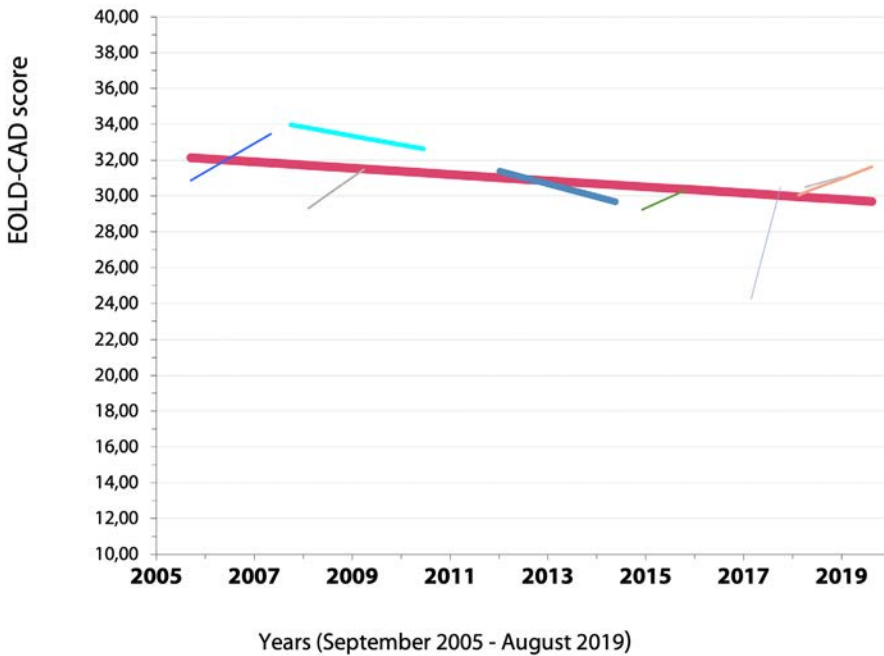
EOLD-SWC= End-of-Life in Dementia Satisfaction with Care, DEOLD=Dutch End Of Life in Dementia, FOLlow-up=Feedback on End-of-Life care in dementia, PACE=Palliative Care in Care Homes Across Europe, DEDICATED=Desired Dementia Care Towards End of Life



- Total
- Study 1 Study 1 Gijsberts et al., n=54
- Study 2 Study 2 Van Soest-Poortvliet et al., n=70
- Study 3 Study 3 DEOLD study, n=248
- Study 4 Study 4 FOLlow-up study, n=537
- Study 5 Study 5 PACE study, n=89
- Study 6 Study 6 Study Proeftuin Dementie, n=16
- Study 7 Study 7 DEDICATED study, n=125
- Study 8 Study 8 Study Marente, n=50

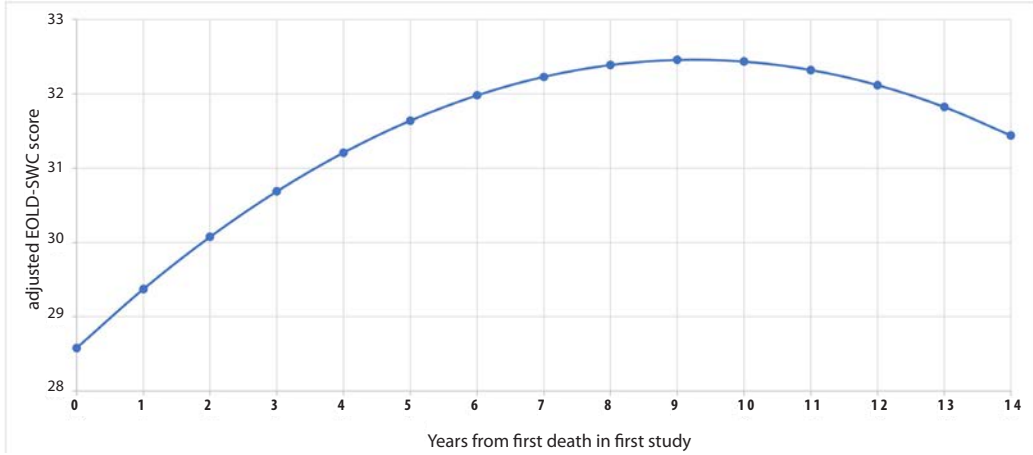
Supplement Figure 2 EOLD-CAD score unadjusted for covariates, with random effects for season and facility

EOLD-CAD=End-of-Life in dementia Comfort Assessment in Dying, DEOLD=Dutch End Of Life in Dementia, FOLLow-up=Feedback on End-Of-Life care in dementia, PACE=Palliative Care in Care Homes Across Europe, DEDICATED=Desired Dementia Care Towards End of Life



- Total
- Study 1 Study 1 Gijsberts et al., n=54
- Study 2 Study 2 Van Soest-Poortvliet et al., n=70
- Study 3 Study 3 DEOLD study, n=248
- Study 4 Study 4 FOLLow-up study, n=537
- Study 5 Study 5 PACE study, n=89
- Study 6 Study 6 Study Proeftuin Dementie, n=16
- Study 7 Study 7 DEDICATED study, n=125
- Study 8 Study 8 Study Marente, n=50

Supplement Figure 3 Quality of care (EOLD-SWC=End-of-Life in Dementia Satisfaction With Care) adjusted model with additional quadratic term for time



Reference list to supplement 1

1. van der Steen JT, van Soest-Poortvliet MC, Gijsberts MJ, et al. [Improved end-of-life care for patients with dementia: greater family satisfaction and possibly greater end-of-life comfort]. *Nederlands tijdschrift voor geneeskunde* 2013;157(17):A5324. [published Online First: 2013/04/26]
2. van der Steen JT, Gijsberts MJ, Knol DL, et al. Ratings of symptoms and comfort in dementia patients at the end of life: comparison of nurses and families. *Palliative medicine* 2009;23(4):317-24. doi: 10.1177/0269216309103124 [published Online First: 2009/04/07]
3. van der Steen JT, Gijsberts MJ, Muller MT, et al. Evaluations of end of life with dementia by families in Dutch and U.S. nursing homes. *International psychogeriatrics / IPA* 2009;21(2):321-9. doi: 10.1017/s1041610208008399 [published Online First: 2009/02/06]
4. van Soest-Poortvliet MC, van der Steen JT, Zimmerman S, et al. Selecting the best instruments to measure quality of end-of-life care and quality of dying in long term care. *Journal of the American Medical Directors Association* 2013;14(3):179-86. doi: 10.1016/j.jamda.2012.09.019 [published Online First: 2012/11/21]
5. van der Steen JT, Ribbe MW, Deliëns L, et al. Retrospective and prospective data collection compared in the Dutch End Of Life in Dementia (DEOLD) study. *Alzheimer disease and associated disorders* 2014;28(1):88-94. doi: 10.1097/WAD.0b013e318293b380 [published Online First: 2013/05/02]
6. Boogaard JA, de Vet HC, van Soest-Poortvliet MC, et al. Effects of two feedback interventions on end-of-life outcomes in nursing home residents with dementia: A cluster-randomized controlled three-armed trial. *Palliative medicine* 2018;32(3):693-702. doi: 10.1177/0269216317750071 [published Online First: 2018/01/19]
7. Van den Block L, Smets T, van Dop N, et al. Comparing Palliative Care in Care Homes Across Europe (PACE): Protocol of a Cross-sectional Study of Deceased Residents in 6 EU Countries. *Journal of the American Medical Directors Association* 2016;17(6):566. e1-7. doi: 10.1016/j.jamda.2016.03.008 [published Online First: 2016/05/11]
8. Pivodic L, Smets T, Van den Noortgate N, et al. Quality of dying and quality of end-of-life care of nursing home residents in six countries: An epidemiological study. *Palliative medicine* 2018;269216318800610. doi: 10.1177/0269216318800610 [published Online First: 2018/10/03]