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Original Study

Family-Perceived Quality of End-of-Life Care and Quality of Dying Among Dutch Nursing Home Residents With Dementia: 2005–2024 Trends

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A B S T R A C T

Objectives: Family ratings of quality of end-of-life (EOL) care increased up to 2019 in a previous study on Dutch nursing home residents with dementia, while quality of dying did not. This study examines if these trends have continued based on newly collected data (2019–2024).
Design: Retrospective observational cohort study.
Setting and Participants: Data (2005–2024) were combined from 8 studies involving 1588 bereaved family members of Dutch nursing home residents.
Methods: The End-of-Life in Dementia–Satisfaction with Care (EOLD-SWC; range 10–40) and the EOLD–Comfort Assessment in Dying (EOLD-CAD; 4 subscales; total score range 14–42) were used to measure bereaved family-perceived quality of EOL care and dying. Mixed models were used to analyze trends over time, with EOLD-SWC and EOLD-CAD scores as the dependent variables, and time of death as an independent variable. A quadratic term and spline analysis were applied to assess nonlinearity.
Results: EOLD-SWC scores increased significantly by 0.117 points per year (CI, 0.042 to 0.192), reaching an estimated 34.4 points by 2024, with a substantial increase in the early years. In contrast, EOLD-CAD total scores remained stable. The dying symptoms subscale increased (0.038 points per year; CI, 0.006 to 0.071) whereas the well-being subscale declined (−0.033 points per year; CI, −0.062 to −0.003) with a sharper decline initially. Subscale scores for "Physical distress" and "Emotional distress" were unchanged.
Conclusions and Implications: Over 18 years, trends in family-perceived quality of EOL care for people with dementia have improved. However, the quality of dying diverged, and 2 subscales changed in opposite directions with a significant decline in the well-being subscale and an increase in the dying symptoms subscale. Future research should explore well-being and expectations over time of what constitutes a "good death" in dementia and palliative care interventions to effectively improve quality of dying.

In western countries, many nursing home residents have dementia and they typically reside there until death.[1,2] Reduced verbal capacity due to the progression of the disease is common and poses significant challenges for palliative care, and thereby the quality of dying.[3-5] Despite the rapidly growing prevalence of dementia worldwide, the evidence for palliative care approaches managing these challenges is still limited for people with advanced dementia.[6,7]

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It is recommended that this palliative care approach prioritizes person-centered care, effective communication, comfort, psychosocial and spiritual support, education for health care providers, and family involvement.[8]

For residents with advanced dementia, family caregivers do not only act as spokespersons, care partners, and decision makers, but their unique knowledge of the resident's life story and preferences is also of great importance.[9] Furthermore, for the family member, recall of the last week of the life of the resident generally endures strongly and affects the grieving process.[10] Given their central roles and perspectives, bereaved family members' assessments of the quality of the end-of-life care and the quality of dying can offer valuable insights to improve EOL care. Validated instruments are available to evaluate both the family-perceived quality of care and quality of dying.[11,12]

Our previous study has shown that family-perceived quality of end-of-life care of the resident with dementia significantly improved over time.[13] Up to 2019, over 14 years, the increase was especially pronounced in the earlier years of the study. Despite this improved appreciation for the quality of care, the family's perception of the quality of dying did not change over time. Notably, the well-being aspect of the dying process significantly decreased over the years. Interpreting the possible paradox behind these differing trends highlighted the need to continue to monitor the evaluations. This study aims to enhance this understanding of the family-perceived trends in quality of care and quality of dying for nursing home residents with dementia by extending previous research with new data up to 2024. Given the advancements in knowledge on and research in palliative care, we hypothesized that the trend in the quality of care shows consistent improvement. This increase is likely less pronounced than before, given the sharper rise in quality of care scores as observed in the earlier years of our previous study. We had no hypothesis as to change in quality of dying based on little understanding of reasons for stability and even decline on its well-being subscale.

Methods

Study Population

This study examined trends based on the addition of newly collected data (2019–2024). In total, this study combined observational data from 8 nationwide or regional studies conducted between September 2005 and February 2024 in Dutch nursing homes (Table 1).[11,13-20] The newly collected data comprise continued data collection within the DEDICATED (Dementia Care Towards End of Life) and Marente studies (studies 7 and 8, Table 1). The DEDICATED study has been continuously collecting data since 2018 and new data were added where the previous study included data up to September 2019. The Medical Ethical Committee of Zuyderland Medical Centre (METCZ20180026, METCZ20190095) determined that this study was not subject to the Medical Research Involving Human Subjects Act (July 29, 2019). Data collection for the Marente study was resumed during the COVID-19 pandemic. The Medical Research Ethics Committee of Leiden University Medical Center had declared the Marente study exempt from the Medical Research Involving Human Subjects Act (WMO; no. P17.214, October 19, 2017). All studies gathered data retrospectively, whereas the DEOLD (Dutch End Of Life in Dementia) study also collected part of the data prospectively (study 3, Table 1). A survey was sent to family members who were listed as the primary contact person for the resident, within 1.5 to 2.0 months after the death of the resident for most of the studies and up to a year after death in 3 studies (studies 5, 6, and 8, Table 1).

The combined data from the studies (2005–2024) included a total of 1588 nursing home residents with dementia, including 28 recently returned surveys of the previous data collection period of the DEDICATED study and 371 new evaluations collected between September 2019 and February 2024. These 1588 cases represent residents from 123 different nursing homes across all provinces of the Netherlands. All nursing home residents included in these studies received medical care by a certified elderly care physician or nurse practitioner.[21]

Measures

The quality of end-of-life care was measured using the End-of-Life in Dementia–Satisfaction with Care (EOLD-SWC) instrument. Because of its strong psychometric properties, it is recommended as the preferred scale for research on quality of care for this population.[11] The EOLD-SWC consists of 10 items evaluating the family caregiver's perspective on the quality of care. Each item is scored from 1 to 4, with responses ranging from "strongly disagree" to "strongly agree." Higher scores indicate better quality of care. Three items are negatively phrased and require reverse coding before calculating the total score. The family member was asked to refer to the last week to last 3 months of the resident's life depending on the individual study (Table 1).

The EOLD- Comfort Assessment in Dying (EOLD-CAD) scale was used to measure the quality of dying, including 14 items across 4 subscales: physical distress, dying symptoms, emotional distress, and well-being. The items are scored from 1 to 3, with response options of "a lot," "somewhat," and "not at all," with a higher score indicating a better perceived quality of dying. The well-being subscale includes 3 positive items—serenity, peace, and calm—which require reverse coding before calculating the total score. Most of the studies asked family members to base their responses on the week leading up to their family member's death, whereas 2 studies asked to refer their responses to the dying process itself (studies 1 and 3, Table 1).

In addition, the survey included patient and family characteristics, and whether the resident was fully dependent on caregivers for eating as an indicator of very severe cognitive impairment equivalent to the highest level on the Cognitive Performance Scale (CPS 6).[22-24] In addition, in studies 1, 2, 3, and 5, dementia severity was assessed using the Bedford Alzheimer Nursing Severity-Scale (BANS-S) (Table 1).

Analysis

Descriptive statistics were examined for both residents and family members across the overall data and within each individual study, including patient characteristics and mean scores for the EOLD-SWC and EOLD-CAD. The Pearson's r correlation coefficient was used to determine the correlation between the 2 EOLD total scores.[25]

To assess the primary outcomes, the total scores of the EOLD-SWC and EOLD-CAD from the overall dataset were analyzed using mixed models. The independent variable was the time of death relative to the first death on September 12, 2005. The total scores of the EOLD-SWC and EOLD-CAD served as the dependent variables. The models incorporated random effects to account for seasonal variations in deaths, using the meteorological seasons, and clustering of residents within nursing homes. For both EOLD scales, a total score was calculated if at minimum two-thirds of the items were answered, with missing items imputed using the mean score per individual. In the DEDICATED study, only the month of death was available in the dataset. For data analysis, we imputed the 14th day for February and the 15th day for other months. In one case in which only the year of death (2020) was recorded, the midpoint of the year, July 2, 2020, was imputed as the date of death.

The models were adjusted for the resident's age and sex, the relationship of the family member to the resident (partner or spouse,

Table 1
Overview of Datasets Combined for Trend Analyses on Quality of Care and Quality of Dying

Study (Main Reference)	Period	Design	Number of Nursing Homes, Area in Netherlands	Number of Residents	Time Questionnaire Sent to Family Caregiver After Death	Study Aim	Time Frame, Referred to:	
							EOLD-SWC	EOLD-CAD
1. Gijsberts et al.	Sep 2005–Jun 2007	Retrospective, observational	4 facilities, west/central	54	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
2. Van Soest et al. Psychometric instrument study	Feb 2008–Apr 2009	Retrospective, observational	14 facilities, west/central	70	2 months	Assess psychometric properties of instruments to evaluate quality of care and death in long-term care	Last month	Last week
3. Van der Steen et al DEOLD Study	Feb 2007–Jul 2010	Prospective and retrospective, observational	40* facilities of 17 health care organizations, nationwide	248	6 weeks	Assess factors associated with quality of care and quality of dying	Last week	During his/her dying, only if present
4. Boogaard et al FOLlow-Up Study	Jan 2012–Jun 2014	Retrospective, cluster randomized controlled trial	18† facilities, nationwide	537	6 weeks	Assessment of effect of feedback strategies in perceived end-of-life care and comfort	Last month	Last week
5. PACE, European study	Dec 2014–Nov 2015	Retrospective, 6 countries also nondementia, observational	25 facilities, stratified sampling, nationwide	89	2 to 4 months	Comparison of palliative care in nursing homes in 6 European countries	Last week	Last week
6. A-M The et al Proeftuin Dementie Friesland	Feb 2017–Oct 2017	Retrospective, observational (intervention not implemented in nursing homes)	4 facilities of 1 health care organization, north of Netherlands	16	6 to 13 months	Improving palliative care with mobile palliative care teams	Last week	Last week
7. DEDICATED (Desired Dementia Care Towards End of Life)	Feb 2018–Feb 2024	Retrospective, observational	12† facilities of 2 health care organization, south of Netherlands	409	6 to 8 weeks	Improving palliative care for people with dementia and caregivers	Last 3 months	Last week
8. Marente	Apr 2018– Dec 2018 & Mar 2020 – Dec 2021	Retrospective, observational	6 facilities of 1 health care organization, west of Netherlands	165	3 to 12 months	Additional data to address research question of possible trend in evaluation end-of-life care	Last week	Last week

FOLlow-up, Feedback on End-of-Life care in dementia; PACE, Palliative Care in care Homes Across Europe.
*Included nursing homes after move.
†Only pre-test and control group in trend analysis.

daughter or son [in-law], and other), the sex of the family member, the region of the Netherlands (urbanized western and central regions with greater staffing challenges vs other regions), and the study design (prospective vs retrospective).

In addition, a quadratic term for time was used to evaluate the fit of a nonlinear model. If nonlinearity was significant, a spline analysis for the unadjusted model was performed to further examine the nonlinear trend. This analysis introduced a knot (point where the spline function connects) to join 2 linear segments. The knot was placed exploratively at the median of the cases (case 794), at 7.69 years after the first death in the overall study. Further, we performed a sensitivity analysis for additional adjustment for the dementia severity using the data about the full dependency in eating. All analyses were performed in IBM SPSS (version 29.0.0.0).

Results

Participant Characteristics

With the newly collected data, the total study included 1588 residents over a period of 18.4 years with a mean age of 85.5 years at their time of death, 66% of whom were female (Table 2). A little over a quarter (28%) were fully dependent in eating, of the 1175 residents with this data available. The mean age of family members was 62.2 years, with 64% being female. Most (66%) were daughters or sons (in-law) of the resident (Table 2). The characteristics in the newly collected and earlier data were similar.

The mean of the complete dataset of the EOLD-SWC total score was 33.5, ranging from 30.2 to 34.4 across studies (Table 3). The mean EOLD-CAD total score was 30.7, ranging from 27.2 to 33.3. The Pearson's r between the 2 EOLD scores was +0.28 ($P < .001$).

Trend Analysis

The mixed model analysis showed a positive trend for quality of care (2005–2024); the unadjusted model demonstrated a significantly increasing EOLD-SWC score of 0.102 points per year (confidence interval (CI), 0.039–0.166) and an adjusted significant increase of 0.117 points per year (CI, 0.042–0.192) (Table 4). The quadratic term for time was significant for both the unadjusted ($P = .002$) and adjusted ($P < .001$) model. Spline analysis showed a significant increase in the EOLD-SWC score of 0.361 points per year (CI, 0.212–0.510) in the first spline segment (2005–2012) comprising half of the cases. This was followed by no significant change, with a small negative coefficient of −0.053 points per year (CI, −0.153 to 0.047) in the second spline segment (2012–2024; comprising the other half of the cases).

The quality of dying, measured by the EOLD-CAD score, showed a significant decrease of −0.099 points per year (CI, −0.176 to −0.023) for the unadjusted model, whereas there was no significant trend in the adjusted model with a smaller negative coefficient of −0.031 (CI, −0.119 to 0.057) (Table 4). This difference was mainly driven by adjustment for the design of retrospective vs prospective study design. A quadratic term for change over time was significant in the unadjusted model ($P = .015$) but was not significant for the adjusted model ($P = .14$).

The EOLD-CAD subscale analysis showed that the subscale "Dying symptoms" significantly increased for the adjusted model with 0.038 points per year (CI, 0.006–0.071) (Table 4). The quadratic term of this subscale was not significant in both models. The subscale well-being significantly decreased over time with a coefficient of −0.040 points per year for the unadjusted model (CI, −0.065 to −0.015) and −0.033 points per year for the adjusted model (CI, −0.062 to −0.003) (Table 4). The analysis including the quadratic term over time was significant in both models. The spline analysis for the well-being component of the dying process, showed a decline of −0.110 points per year (CI, −0.174 to −0.047) for the first segment, followed by no significant change with a negligible negative coefficient of −0.006 points per year (CI, −0.043 to 0.031) in the second spline segment.

No significant trends were observed in the other EOLD-CAD subscale scores. The sensitivity analysis regarding the severity of the dementia, measured by full dependency in eating, yielded similar predicted values for the adjusted and unadjusted models for both the EOLD-SWC and EOLD-CAD scales.

Table 2
Total Scores for Quality of Care (EOLD-SWC; n = 1552) and Quality of Dying (EOLD-CAD; n = 1244) Across Studies

Study, 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	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	33.6 (5.2)	391/409	30.5 (5.6)	340/409
8. Marente	34.1 (5.1)	160/165	30.5 (5.8)	146/165

FOLlow-up, Feedback on End-of-Life care in dementia; PACE, Palliative Care in care Homes Across Europe.

Discussion

Main Findings

Trends have continued for 18 years, showing an improvement in family-perceived quality of end-of-life care for people with dementia residing in nursing homes, whereas we found no change in the quality of dying overall. The quality of care, as measured by the EOLD-SWC scale, improved during 2005–2024, but with no further increase in the later years. The total increase in the EOLD-SWC scores to approximately 34.4 points in 2024 reflects a high level of perceived quality of end-of-life care, considering that EOLD-SWC ranges from 10 to 40 points.[26,27] The stability of the quality of dying scores in the previous data collection (2005–2019), assessed by the EOLD-CAD instrument total score, was unchanged with the addition of the newly collected data up until 2024. At the same time, the EOLD-CAD subscale analysis indicated a significant improvement in the dying symptoms subscale scores over the whole study with the addition of the newly collected data (2019–2024), while still showing a significant decline in the well-being subscale scores.

The nonlinearity in the trend regarding the quality of care, with a steeper and significant increase in the first half of the study only, might have been a result of growing interest in the topic of palliative care since it was integrated into standard health care in the Netherlands in the late 1990s.[28] The more stable trend, as shown in the spline analysis during the second half of the study, may be due to a ceiling effect, as 12% of all EOLD-SWC scores then reached the maximum of 40 points.

This stability in the overall scores regarding the quality of dying along with the improvement in the dying symptoms subscale, suggests that while symptom control has advanced, other aspects of comfort at the end of life may not have kept pace. The continuous decline in the subscale well-being indicates that residents may be experiencing less peace and serenity, and were less calm during dying, despite better management of physical symptoms.

This diverging trend could be influenced by the perception and expectations of what constitutes a "good death." This perception

Table 3
Characteristics of Nursing Home Residents Who Died With Dementia and Their Relatives

Mean (SD) or %, [n]	Total all Studies	1. Gijsberts	2. Van Soest	3. DEOLD	4. FOLlow-Up	5. PACE	6. Proeftuin Dementie	7. DEDICATED	8. Marente
Number of residents	1588	54	70	248	537	89	16	409	165
Age, mean number of years; (SD) [n]	85.5 (7.5) [1575/1588]	85.1 (5.8) [54/54]	88.8 (5.9) [67/70]	85.6 (7.1) [244/248]	84.9 (8.1) [535/537]	85.6 (7.2) [89/89]	85.4 (7.5) [15/16]	85.0 (7.6) [409/409]	86.9 (7.0) [162/165]
Female, % [n]	66 [1050/1588]	80 [43/54]	89 [62/70]	67 [165/248]	68 [366/537]	60 [53/89]	50 [8/16]	60 [245/409]	66 [108/165]
Severity of dementia, BANS-S mean score, (SD), [n]	17.1 (4.0) [428/1588]	18.6 (3.3) [54/54]	17.9 (4.2) [70/70]	16.3 (3.7) [248/248]	Not available	17.9 (4.9) [56/89]	Not available	Not available	Not available
Severe dementia, BANS-S score 17 or higher % [n]	54 [230/428]	83 [45/54]	73 [51/70]	41 [102/248]	Not available	57 [32/56]	Not available	Not available	Not available
Full eating dependency (CPS 6), % [n]	28 [329/1175]	33 [16/48]	38 [21/54]	26 [61/237]	29 [155/529]	33 [18/55]	Not available	25 [34/138]	21 [24/114]
Caregiver female, % [n]	64 [1013/1581]	61 [33/54]	67 [47/70]	61 [151/246]	62 [331/537]	68 [60/88]	63 [10/16]	64 [261/406]	73 [120/164]
Age caregiver, mean number of years (SD) [n]	62.2 (10.9) [1519/1588]	Not available	60.6 (8.5) [70/70]	60.6 (11.2) [246/248]	62.7 (11.8) [533/537]	63.4 (11.0) [88/89]	65.3 (9.8) [16/16]	62.4 (10.2) [403/406]	62.0 (10.0) [163/165]
Relationship caregiver, % [n]									
Spouse	19 [305]	12 [6]	6 [4]	19 [46]	21 [113]	23 [20]	19 [3]	22 [87]	16 [26]
Child	66 [1043]	71 [37]	87 [61]	66 [161]	63 [338]	60 [53]	50 [8]	65 [264]	73 [120]
Other	15 [231]	17 [9]	7 [5]	16 [38]	16 [86]	18 [16]	31 [5]	13 [54]	12 [19]

FOLlow-up, Feedback on End-of-Life care in dementia; PACE, Palliative Care in care Homes Across Europe.

often emphasizes a painless death experience as a core element; however, family caregivers additionally consider emotional distress, such as sadness, together with personhood and dignity as crucial factors alongside the physical symptoms.[29-31] In the context of dying with dementia, achieving a peaceful and comfortable death involves addressing a range of aspects, including psychological well-being, physical comfort, and basic needs such as being clean and having privacy.[32] Furthermore, the reality of the death might not meet initial expectations of the family caregiver. In view of the highly valued concepts of autonomy and dignity in the Netherlands, together with the complicated nature of dementia in the ability to exercise autonomy and control: these ideals may influence the expectations around a good death.[33] These possible varying perspectives and expectations highlight the complexity of what entails a "good death" for people with dementia.

In addition, family-perceived quality of death has been found to be more closely related to the communication between family members and professional caregivers than to the actual frequency of symptoms.[34] This might suggest that although physical symptom management has improved, the overall sense of well-being is more affected by poor communication. Improving communication with families could help manage expectations more effectively and improve their perception of the quality of dying.[34] Moreover, it is possible that advancements in symptom management highlight other unmet needs, such as emotional and psychological support. As family caregivers become increasingly aware of how physical symptoms are managed, they may become more aware of the emotional distress.

Increased use of continuous palliative sedation could affect perceptions of quality of care and dying, which we could not examine in this study.[35] In the Netherlands, the frequency of palliative sedation has risen notably between 2005 and 2015, particularly among patients older than 80.[36] Although this trend is not specific to nursing home residents, it may reflect broader developments in the medicalization of dying and shifting expectations of palliative care among family caregivers. Previous studies support this hypothesis by showing that physicians can experience pressure from patients or relatives to initiate palliative sedation, possibly due to a decreasing tolerance for visible symptom burden during dying.[37,38] Future research should explore how symptom management and palliative sedation practices impact symptom control, emotional well-being, and family perceptions of quality of dying in dementia.

Strengths and Limitations

With the addition of almost 400 new evaluations (2019–2024), we studied more than 1500 perspectives of bereaved family members over more than 18 years. The observational nature of the study, without any intervention or modifications to the EOLD scales, allows for extensive assessment of trends in end-of-life research. In addition, sophisticated statistical analysis to assess nonlinearity was performed to gain a more comprehensive understanding of the actual trends.

The EOLD-SWC and EOLD-CAD instruments used to assess the primary outcomes have been recognized as preferred scales, with the EOLD-SWC considered as one of the most reliable tools for evaluation of the quality of end-of-life care.[11,12,39] Despite the consistent use of EOLD instruments across all studies, variations in recruitment methods and the time periods referenced in the EOLD questionnaires may introduce inconsistencies.

Other limitations of this study include the potential for confounding by unmeasured factors, such as the quality of the caregiver-resident relationship.[40] Of note, dementia severity could be an important confounder[41-43] but did not appear to be a confounding factor, as indicated by our sensitivity analysis. Further, in our observational study, we did not measure or test possible explanatory factors such as changes in pharmacological and nonpharmacological treatments.

Conclusions and Implications

This study analyzed the continuation of family-perceived trends in the quality of end-of-life care and the quality of dying of nursing home residents with dementia, with additional data from almost 400 bereaved family members (2019–2024). Combined with previously collected and analyzed evaluations, 1588 family evaluations were included. The increase in scores regarding the quality of care for the overall study (2005–2024) followed a nonlinear trend with a significant rise during the first half of the study and, subsequently, little or no further improvement. The quality of dying overall remained stable. Two quality of dying subscales, however, changed in opposite directions: with significant improvement in dying symptoms, while the decline in well-being remained significant. This discrepancy may indicate a gap between the expectations and perceptions regarding a good death. This study underlines the importance of policies on monitoring family-reported quality

Table 4
Trends in Total and Item Quality of Care Scores (EOLD-SWC) and in Total and Subscale Quality of Dying Scores (EOLD-CAD) Q5

	Mean (SD) [n]	Trend; Coefficient (95% CI) Unadjusted	Trend; Coefficient (95% CI) Adjusted
EOLD-SWC total*	33.49 (5.13) [1552]	***0.102* (*0.039 to 0.166*)**	***0.117* (*0.042 to 0.192*)**
a. I felt fully involved in all decision making	3.41 (0.67) [1559]	0.007 (−0.001 to 0.015)	0.008 (−0.002 to 0.017)
b. I would probably have made different decisions if I had had more information	3.31 (0.74) [1520]	0.005 (−0.004 to 0.014)	0.010 (−0.001 to 0.020)
c. All measures were taken to keep my relative comfortable	3.47 (0.67) [1552]	***0.013* (*0.005 to 0.022*)**	***0.017* (*0.007 to 0.026*)**
d. The health care team was sensitive to my needs and feelings	3.37 (0.66) [1530]	***0.014* (*0.005 to 0.022*)**	***0.011* (*0.001 to 0.021*)**
e. I did not really understand my relative's condition	3.39 (0.79) [1534]	***0.015* (*0.006 to 0.024*)**	***0.015* (*0.005 to 0.026*)**
f. I always knew which doctor or nurse was in charge of my relative's care	3.04 (0.79) [1547]	***0.010* (*0.000 to 0.021*)**	0.009 (−0.003 to 0.020)
g. I felt that my relative got all necessary nursing assistance	3.44 (0.65) [1554]	***0.014* (*0.006 to 0.022*)**	***0.018* (*0.009 to 0.028*)**
h. I felt that all medication issues were clearly explained to me	3.27 (0.72) [1534]	***0.008* (*0.000 to 0.017*)**	***0.011* (*0.001 to 0.021*)**
i. My relative was receiving all treatments or interventions that he or she could benefit from	3.39 (0.66) [1547]	***0.011* (*0.003 to 0.018*)**	***0.012* (*0.002 to 0.021*)**
j. I feel that my relative needed better medical care at the end of his or her life	3.42 (0.78) [1539]	0.003 (−0.005 to 0.012)	0.007 (−0.004 to 0.017)
EOLD-CAD total†	30.71 (5.70) [1244]	***−0.099* (*−0.176 to −0.023*)**	−0.031 (−0.119 to 0.057)
1. Physical distress‡ (items 1, 2, 3, 4, score range 4−12)§	8.26 (2.10) [1293]	***−0.037* (*−0.064 to −0.011*)**	−0.017 (−0.047 to 0.014)
2. Dying symptoms‖ (item 4 [part of 2 subscales], 5, 6, 7, score range 4−12)§	8.94 (2.20) [1263]	0.018 (−0.010 to 0.045)	***0.038* (*0.006 to 0.071*)**
3. Emotional distress** (items 8, 9, 10, 11, score range 4−12)§	9.46 (2.22) [1245]	***−0.044* (*−0.073 to −0.015*)**	−0.023 (−0.058 to 0.011)
4. Well-being†† (items 12, 13, 14, score range 3−9)§	6.10 (1.97) [1250]	***−0.040* (*−0.065 to −0.015*)**	***−0.033* (*−0.062 to −0.003*)**

Italics and bold = $P < .05$. Cronbach's α.
*EOLD-SWC total: 0.89.
†EOLD-CAD total: 0.82.
‡EOLD-CAD subscale Physical distress: 0.62.
§Volicer L, Hurley AC, Blasi ZV. Scales for evaluation of end-of-life care in dementia. Alzheimer Dis Assoc Disord 2001;15:194−200.
‖EOLD-CAD subscale Dying symptoms: 0.69.
**EOLD-CAD subscale Well-being: 0.90.
††EOLD-CAD subscale Emotional distress: 0.77.

indicators over time, emphasizing the value of family-perceived outcomes as key quality metrics in evaluating and guiding end-of-life care in dementia. The findings also highlight the need for ongoing observation and further research into the concept of a good death in dementia, the indications and effects of medication and palliative sedation, and how interdisciplinary palliative care can address persistent symptom burden. In clinical practice, it is important to understand how the family perceives the resident's comfort and peace, to better align expectations with appropriate treatment during the dying process.

Disclosure

The authors declare no conflicts of interest.

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