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## Brief Report

# Families' Experiences With End-of-Life Care in Nursing Homes and Associations With Dying Peacefully With Dementia



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## A B S T R A C T

**Key words:**  
Dementia  
end-of-life care  
family caregivers  
nursing homes  
quality of dying

**Objectives:** To examine family caregivers' experiences with end-of-life care for nursing home residents with dementia and associations with the residents dying peacefully.

**Design:** A secondary data analysis of family caregiver data collected in the observational Dutch End of Life in Dementia (DEOLD) study between 2007 and 2010.

**Setting and participants:** Data were collected at 34 Dutch nursing homes (2799 beds) representing the nation. We included 252 reports from bereaved family members of nursing home residents with dementia.

**Measures:** The primary outcome was dying peacefully, assessed by family members using an item from the Quality of Dying in Long-term Care instrument. Unpleasant experiences with end-of-life care were investigated using open-ended questions. Overall satisfaction with end-of-life care was assessed with the End-of-Life Satisfaction With Care (EOLD-SWC) scale, and families' appraisal of decision making was measured with the Decision Satisfaction Inventory. Associations were investigated with multilevel linear regression analyses using generalized estimating equations.

**Results:** Families' reports of unpleasant experiences translated into 2 themes: neglect and lack of respect. Neglect involved facing inaccessibility, disinterest, or discontinuity of relations, and negligence in tailored care and information. Lack of respect involved perceptions of being purposefully disregarded, an insensitive approach towards resident and family, noncompliance with agreements, and violations of privacy. Unpleasant experiences with end-of-life care were negatively associated with families' perceptions of the resident dying peacefully. Families' assessment of their relative dying peacefully was positively associated with satisfaction with end-of-life care and decision making.

**Conclusions/Implications:** Families' reports of unpleasant experiences with end-of-life care may inform practice to improve perceived quality of dying of their loved ones. Humane and compassionate care and attention from physicians and other staff for resident and family may facilitate recollections of a peaceful death.

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Families of people with dementia fulfil an important caregiving role that usually continues after nursing home admission.<sup>1</sup> Dementia may inflict anticipatory grief in families before actual bereavement because of the cognitive and functional deterioration associated with the disease.<sup>2,3</sup> Families' grief reactions before and after bereavement are influenced by the extent to which families are satisfied with end-of-life care and their experiences around the final days of life of their relative with dementia.<sup>2,3</sup> Caregiver burden and distress in family caregivers have been described mainly in relation to earlier stages of dementia and community settings.<sup>4,5</sup>

In most Western countries, the majority of people with dementia eventually die in nursing homes or other long-term care facilities.<sup>6</sup> Families of people with dementia are often involved in health care decision making because of their relatives' cognitive impairments.<sup>7</sup> Especially at the end of life, surrogate decision makers may face ethical challenges receiving insufficient guidance from health care professionals and experiencing uncertainty regarding the wishes of their loved one.<sup>8</sup> Offering emotional support and information to families is particularly important in caring for individuals with dementia at the end of life.<sup>9–11</sup>

An indicator for quality of dying in long-term care settings is dying peacefully.<sup>12</sup> Peaceful dying involves spiritual well-being and meaningfulness of life,<sup>12</sup> which may be reflected in calmness, nearness to one's beloved, and experiences of inner harmony.<sup>13</sup> Spiritual and emotional support may offer consolation and aid families to find comfort and peace beyond the painfulness of losing a loved one with dementia.<sup>14</sup>

Previous research indicated that only half of the people with dementia in long-term care facilities died peacefully according to their relatives.<sup>13,15</sup> De Roo and colleagues<sup>13</sup> found that dying peacefully was related to the residents' optimism and families' perception that enough nurses were available in the nursing home. However, families' own experiences with the provision of care may contribute to their perceptions of a peaceful death of their loved one and have not been studied extensively.<sup>11,15</sup> Therefore, the current study aims to investigate unpleasant experiences with end-of-life dementia care and associations with dying peacefully.

## Methods

A secondary data analysis was performed using data from the Dutch End of Life in Dementia (DEOLD) study.<sup>16</sup> This study investigated families' and physicians' perceptions of the quality of dying of nursing home residents with dementia, families' satisfaction with end-of-life care and decision making, and the factors associated with these outcomes. The protocol of the DEOLD study received approval from the Medical Ethics Review Committee of VU University Medical Center, Amsterdam.

### Study Design, Setting, and Data Collection

A purposive sample of nursing homes was recruited across all provinces to represent the nation, seeking variability in family caregivers' publicly available ratings of quality of care.<sup>16</sup> Data were collected between 2007 and 2010, by physician teams of 17 Dutch nursing home organizations. The teams covered 34 facilities (2799 beds). Questionnaires were completed by families 2 months after the death of the resident.

### Population

Family caregivers were eligible if (1) their relative resided on a psychogeriatric ward in a participating nursing home, (2) their relative was diagnosed with dementia by a physician, and (3) they were able to understand and write Dutch or English.<sup>16</sup>

## Measures

Demographic variables included resident's age at death, gender, and type of dementia, participant's age, gender, and level of education, family relationship, and time spent (by the family member) with the resident in the final week of life.

Dying peacefully was a primary outcome, measured with an item from the Quality of Dying in Long-term Care instrument.<sup>13,17</sup> This item concerned the last month of life and was measured on a 5-point Likert-type scale, with higher scores indicating a more peaceful death. Analyzing associations with comfort measured with the Comfort Assessment in Dying (EOLD-CAD) scale had been planned, as it is a valid and reliable measure for quality of dying.<sup>18</sup> However, we refrained from the analysis because when the family was not present at the moment of death, a skip pattern resulted in missing values and low power.

Two open-ended questions were used inquiring about the occurrence of insufficient care or any unpleasant experiences in the care during the last week of life:

1. If anything else was missing in the care provided to your loved one and to you, could you describe what was most important? Did this (also) concern care in the last week of life?
2. Did you have any unpleasant experiences with the care provided to your loved one and to you? (Yes, namely: ...) Did this (also) concern care in the last week of life?

Independent variables included families' after-death appraisal of the decision-making process and decisions that were made within the last 6 months before death, measured with the Decision Satisfaction Inventory, and satisfaction with care in the last week of life assessed with the End-of-Life in Dementia-Satisfaction With Care (EOLD-SWC) scale.<sup>16</sup> The Decision Satisfaction Inventory is a reliable and valid instrument<sup>19</sup> and the EOLD-SWC scale<sup>20</sup> has shown excellent psychometric properties.<sup>18</sup> On both instruments, higher scores indicate greater satisfaction.

## Analyses

Descriptive statistics of demographic data and the other variables of interest were generated using IBM SPSS statistics version 24.0 (IBM Corp, Armonk, NY). Answers to the open-ended questions were analyzed using thematic analysis.<sup>21</sup> Two authors (L.V. and J.T.S.) read answers thoroughly to familiarize themselves with the data. The authors initially performed open coding and independently coded the answers. Next, the authors compared their independent coding series, broadening initial codes. Any discrepancies were discussed to reach consensus and to fine-tune individual codes and categories. Lastly, axial coding clustered the main categories into the ultimate themes. A native English speaker checked the translation of themes and citations.

Multilevel linear regression analyses were conducted using the generalized estimating equations method to investigate associations between families' unpleasant experiences with care, their overall satisfaction with care, and their satisfaction with the decision-making process and care decisions, and dying peacefully. Population-average models were estimated,<sup>22</sup> using an independent correlation structure, and clustering of residents within different care facilities was accounted for. If less than one third of the items on the SWC or Decision Satisfaction Inventory were missed, the resident's total score was calculated after imputation with the resident's mean item score. Missing values in the control variables were handled using multiple imputation.<sup>23</sup> Five data sets were imputed using a fully conditional specification method. Demographic variables were entered into adjusted models to control for possible confounding. We performed sensitivity analyses to examine if associations were stable over time by

also adjusting for time of death. For the adjusted models, pooled estimates were calculated from the imputed data sets.

## Results

In total, family members of 252 residents completed the after-death assessment (Table 1). The participants' mean age was 60.8 (standard deviation = 11.1, range 35.8, 90.0); 61.1% were female. The mean age at death of their relatives with dementia was 85.6 (standard deviation = 7.2, range 46.5, 100.9); 66.3% were female.

Of the 252 family members, 42 (17.0%) reported 1 or more unpleasant experiences with care during the last week of their relative's life. Two main themes represented the experiences. Theme 1, "neglect," emerged from 34 (13.5% of the total) cases. Theme 2, "lack of respect," emerged from 16 (6.3%) cases.

Table 2 shows examples of family caregivers' reports that formed the main themes and subthemes. Neglect refers to families' experiences of professional caregivers' negligence in providing tailored care for their relative and providing information about their relatives' disease or process of dying. Moreover, this theme entails a perceived lack of contact with professional caregivers, perceptions of not being properly informed to understand care or treatment, dissatisfaction with communication between staff, and perceptions of shortages on staff and time. Reports regarding this theme of neglect often involved physicians being considered inaccessible and uninvolved or physicians' shift changes. The second theme, lack of respect, involves families' experiences of their relative or themselves not being treated respectfully, or insensitively by health care staff, their relatives' and their own privacy being violated, noncompliance of staff with agreements about care and treatment, and perceptions of being purposefully disregarded.

Table 3 shows that there were significant associations between dying peacefully and families' satisfaction with care ( $B = 0.09$ ,  $P < .001$ ), satisfaction with the decision-making process ( $B = 0.04$ ,  $P = .002$ ), satisfaction with decisions ( $B = 0.15$ ,  $P = .001$ ), and unpleasant experiences with care in the final week of the residents' life ( $B = -0.75$ ,  $P = .016$ ). In the adjusted models, significant associations remained between the variables of interest and dying peacefully. When all variables of interest were entered to compete in a fully adjusted model, only the significant association with overall satisfaction with care with dying peacefully remained ( $B = 0.10$ , 95% confidence interval = 0.05, 0.16, standard error = 0.03,  $P < .001$ ). The coefficients were similar in the sensitivity analyses, which suggests the associations did not change over time.

## Discussion

Families of nursing home residents with dementia essentially complained about 2 issues in the care of their loved one at the end of life: a feeling that they or—mostly—their loved one was being neglected, and a feeling they were treated in a disrespectful manner. Families reporting unpleasant experiences were more likely to believe that their relative did not die peacefully. Slightly more than half of the family members indicated that their relative had died peacefully.<sup>13</sup> Our findings suggest that satisfaction with care and decision making and experiencing neglect or a lack of respect in the last week of life impact on how peaceful dying had been according to bereaved family caregivers. Families' satisfaction with care was strongly associated with dying peacefully and as a broad measure assessed with the EOLD-SWC, with excellent psychometric properties,<sup>18</sup> likely incorporates experiences with care and decision making.

In line with our findings, Hennings and colleagues<sup>11</sup> found in their review that families witnessing the end of life of a loved one with dementia in nursing homes need supportive communication, adequate information, and sufficient attention from professional

**Table 1**  
Characteristics of Family Members and Residents

	Count (n)	Percentage (%)	Missing (%)
<b>Family characteristics</b>			
Gender			
Female	154	61.1	0
Male	98	38.9	
Highest completed education			
None or primary/elementary school	16	6.5	1.6
(High school preparing for) technical/trade school	130	51.6	
High school preparing for BSc or MSc	27	10.7	
BSc or MSc degree	75	29.8	
Family relation with resident			
Son or daughter	153	61.0	1.2
Partner or spouse	49	19.5	
Cousin	15	6.0	
Brother or sister	6	2.4	
Representative	3	1.2	
Grandson or daughter	2	0.8	
Other	23	9.2	
Time spent with resident during the last week of life			
None	8	3.2	0
≤7 h	46	18.3	
8–14 h	34	13.5	
15–21 h	39	15.5	
22–28 h	37	14.7	
≥28 h	88	34.9	
<b>Resident characteristics</b>			
Gender			
Female	167	66.3	0
Male	85	33.7	
Type of dementia			
Alzheimer's	100	40.7	2.4
Vascular	67	27.2	
Alzheimer's and vascular	42	17.1	
Lewy body	15	6.1	
Other combinations	22	8.9	
Dying peacefully <sup>13</sup>			
Completely	72	30.9	7.5
Quite a bit	59	25.3	
A moderate amount	42	18.0	
A little	35	15.0	
Not at all	25	10.7	
Measures <sup>a</sup>			
	M	SD	
EOLD-SWC, satisfaction with care <sup>b</sup>	32.5	5.4	2.8
DSI <sup>c</sup>			
Satisfaction with decision-making process	67.7	18.7	8.7
Satisfaction with decisions	75.6	19.7	9.0

DSI, Decision Satisfaction Inventory; EOLD-SWC, End-of-Life in Dementia-Satisfaction With Care; M, mean; SD, standard deviation.

<sup>a</sup>Missing values for these measures are after imputation with mean item scores if less than one third of the items were missing.

<sup>b</sup>Possible range of EOLD-SWC scores = 0, 40.

<sup>c</sup>Possible range of standardized DSI scores = 0, 100.

caregivers. Furthermore, although perceived staff shortage is a source of concern,<sup>13,24</sup> families tend to sympathize with nursing staff.<sup>24,25</sup> In our study, unpleasant experiences with care often involved physicians' inaccessibility and changes in physicians responsible for the care. Boogaard and colleagues<sup>26</sup> found that satisfaction with care relates to families' trust in professional caregivers in Israel, and that families trust physicians more than nurse aides. Perhaps families' strong trust in physicians and their expectations cause disappointment when their needs for guidance and support are not met, especially at the end of life.<sup>25</sup> Conversely, available and easily accessible physicians may allow for developing a relationship, promoting more pleasant experiences with care. This corresponds with previous findings indicating that Dutch and US physicians who are present longer in the nursing home

**Table 2**  
Example Quotes From Participants per Theme and Subtheme Describing Insufficient Care or Unpleasant Experiences With Care

Main Theme and Subthemes	Example Quotes From Participants
Neglect	
Care or treatment not understood	"We think that the morphine should have been increased earlier." "A night shift [nurse] was a bit too casual (in my opinion) about structurally administering morphine."
Not properly informed	"Better counseling regarding people with dementia, further explanations about medication." [missed from physicians]
Poor communication between health care professionals/staff between shifts	"It is a very delicate matter that everyone receives and provides the same information. This might be tricky at times, but it is important." "The one thing that bothers me is that there had been no information transfer from Sunday night to Monday morning, with the result that the nursing staff was unaware that my mother was dying."
Suboptimal care and treatment	"In the final days, mother became extremely dehydrated; dry and painful mouth, I had to buy Q-tips with glycerin and lemon myself." "My mother-in-law experienced a lot of pain during the final months; the physician had difficulty finding out why; [resident] received painkillers but that was not enough."
Lack of contact with care providers	"The only time I met the physician associated with [name of the nursing home], was when signing the death certificate."
Shortage on staff/time	"A bit more time for having a conversation, a supporting or kind word. They tried very hard, but more staff is required."
Lack of respect	
Violation of privacy	"My father had to share his room with someone else. It was only on Saturday night, prior to the Monday he passed away, that he was given a separate room." "This was shared with us in the hallway, in the presence of other visitors."
Insensitive approach	"Communicating with some more respect and compassion."
Noncompliance with agreements	"In the final week of my father's life, a deputy physician initiated antibiotic treatment without consultation, despite the fact that it was previously agreed that this would not happen anymore."
Being purposefully disregarded	"I indicated several times that my father-in-law did not handle medication such as haloperidol well at all, following previous experiences with the consequences. It was continued anyway."

are more likely to be aware of family preferences and to honor these preferences.<sup>27</sup>

Perceived abandonment of people with dementia living in nursing homes may not be limited to the final phase, and preserving personhood in dementia care is a virtuous pursuit.<sup>28</sup> Families may experience emotional disruption and helplessness when sensitive, humane attention for a dying loved one is missed. Dedicated, involved physicians and other staff; genuine, respectful, and sensitive attention; and continuity in care and communication may help facilitate families of nursing home residents dying with dementia experience peace for both themselves and their loved ones. At the end of caring for a loved one with dementia and having dealt with multiple losses, recollections of a peaceful death may offer consolation.

### Strengths and Limitations

There is a dearth of literature on factors contributing to people with dementia dying peacefully.<sup>15</sup> To our knowledge, this is the first study to investigate families' specific experiences with end-of-life care in relation to their judgment of a relative with dementia dying peacefully. It is important to understand families' needs in their own

right. The DEOLD data represented nationwide data from nursing home residents with dementia.<sup>16</sup> Four researchers were involved in the analysis. We used a single item from the Quality of Dying in Long-term Care instrument as the outcome measure. The outcomes represent families' judgment only. The qualitative analysis in this study was limited to analysis of open-ended items in an otherwise large questionnaire, and some responses were brief.

### Conclusion and Implications

Families' unpleasant experiences with end-of-life care relate to perceptions of a less peaceful death of their loved one with dementia. Overall, these unpleasant experiences concern disappointment through the absence of humane, compassionate care and attention for a loved one nearing death. Evaluating family members' experiences with end-of-life care is valuable in both research and practice, as their perspectives may create awareness among health care professionals and inform strategies for improving care provision in nursing homes. Responding to the families' needs may improve perceived quality of dying of residents with dementia.

**Table 3**  
Adjusted and Unadjusted Associations With Dying Peacefully

	Unadjusted, B (95% CI)	Adjusted, B (95% CI)	n
Satisfaction with care (EOLD-SWC)*	0.09 (0.06, 0.12) <sup>†</sup>	0.08 (0.05, 0.11) <sup>†</sup>	228
Satisfaction with decisions (DSI)*	0.15 (0.07, 0.24) <sup>†</sup>	0.16 (0.07, 0.24) <sup>†</sup>	122
Satisfaction with the decision-making process (DSI)*	0.04 (0.01, 0.06) <sup>‡</sup>	0.04 (0.01, 0.07) <sup>‡</sup>	121
Any unpleasant experiences	−0.75 (−1.34, −0.14) <sup>§</sup>	−0.73 (−1.37, −0.09) <sup>§</sup>	229
Neglect	−0.66 (−1.22, −0.11) <sup>§</sup>	−0.66 (−1.22, −0.09) <sup>§</sup>	229
Lack of respectful treatment	−0.83 (−1.54, −0.13) <sup>§</sup>	−0.65 (−1.47, 0.16)	229

CI, confidence interval; DSI, Decision Satisfaction Inventory; EOLD-SWC, End-of-Life in Dementia-Satisfaction With Care.

The adjusted models included the following variables: resident's age at death, gender, and type of dementia; participant's age, gender, and level of education, family relationship, and time spent (by the family member) with the resident in the final week of life. The outcome measure dying peacefully involves the final month of life. EOLD-SWC scores involve satisfaction with care during the final week of the resident's life. DSI scores involve satisfaction with the decision and the decision-making process when a decision was being made in the final 6 months of the resident's life (57.8%). Any unpleasant experiences refer only to the final week of the resident's life.

\*The coefficient estimates are per unit increase of the independent variable.

<sup>†</sup>Significant at  $P < .001$ .

<sup>‡</sup>Significant at  $P < .005$ .

<sup>§</sup>Significant at  $P < .05$ .

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