# How Is End-of-Life Care With and Without Dementia Associated With Informal Caregivers' Outcomes?

American Journal of Hospice & Palliative Medicine<sup>®</sup> 2019, Vol. 36(11) 1008-1015 © The Author(s) 2019 © ① ① S Article reuse guidelines: sagepub.com/journals-permissions DOI: 10.1177/1049909119836932 journals.sagepub.com/home/ajh **SAGE** 

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#### Abstract

**Background:** Palliative care for older people with life-limiting diseases often involves informal caregivers, but the palliative care literature seldom focuses on the negative and positive aspects of informal caregiving. **Objective:** To assess the association of proximity to end of life (EOL) and dementia caregiving with informal caregivers' burden of care and positive experiences and explain differences in outcomes. **Design:** Data on 1267 informal caregivers of community-dwelling older people were selected from a nationally representative cross-sectional survey and analyzed using analysis of variance and multivariable regression analyses. **Measurements:** The Self-Perceived Pressure from Informal Care Scale and the Positive Experiences Scale were administered to assess caregiver burden and positive experiences with providing care. **Results:** Dementia care, both at EOL and not at EOL, was associated with the most caregiver burden relative to regular care. Dementia care not at EOL was associated with the fewest positive experiences, and EOL care not in dementia with the most positive experiences. Only the differences in burden of care could be explained by variables related to stressors based on Pearlin stress-coping model. **Conclusions:** Informal caregivers of people with dementia are at risk not only of high caregiver burden but also of missing out on positive experiences associated with caregiving at EOL. Future research should examine how dementia-related factors reduce positive caregiving experiences, in order to make palliative care a positive reality for those providing informal care to community-dwelling persons with dementia.

#### Keywords

dementia, informal care, palliative care, burden of care, positive experiences with care, quality of care

## Introduction

Increased life expectancy and improved medical care contribute to the fact that many older adults are dying from or living with slowly progressing life-limiting diseases,<sup>1</sup> increasing the demand for palliative care for this population. Palliative care involves both the patient and the informal caregiver,<sup>2</sup> yet palliative care studies have to date seldom focused on support needs and informal caregiver outcomes.

Considerable research has documented a high caregiver burden and specific needs regarding information on end-of-life (EOL) treatment decisions, respite care, and psychological support among those caring at home for an older person with lifelimiting diseases at EOL.<sup>3-5</sup> Informal caregiving involving dementia, in particular, is associated with negative physical and psychological health outcomes of those involved.<sup>6</sup> However, informal caregiving can also (at times) be a rewarding and satisfying experience for caregivers.<sup>7,8</sup> Caregiver burden and positive experiences are assumed to be separate care outcomes, which differ according to the nature of the care relationship and intensity of caregiving.<sup>9</sup> To date, positive experiences of caregiving at EOL as a means of supporting informal caregivers of older adults with life-limiting diseases living at home have received limited attention.

The aim of this study was first, to assess the association between a care recipient being at EOL (or not) and informal caregiver burden and positive experiences, with and without dementia. Inspired by the stress-coping model of Pearlin et al,<sup>10</sup>

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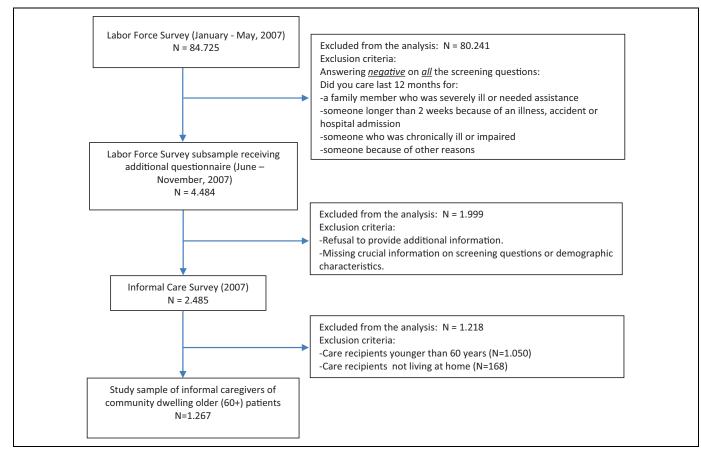


Figure 1. Flowchart of sampling.

we considered caregiver outcomes such as burden of care and positive experiences as a result of overall stress experienced by an informal caregiver. We assumed both outcomes to be associated with stressors and resources in the care context, in addition to caregivers' background characteristics. Examples of stressors are the health of the care recipient and the intensity of care provision. Resources in the social context include help provided by other caregivers and, unlike previous models, variables assessing the process of mobilization and evaluation of support.

## Methods

Data for the analyses were drawn from a large, nationally representative study on informal care carried out by The Netherlands Institute for Social Research in 2007.<sup>11</sup> The respondents for this study were selected from a population-based Labor Force Survey (N = 84725) using a 2-step procedure. First, respondents were asked to identify whether they had provided care in the past 12 months to (1) a family member who was seriously ill or needed assistance; (2) someone for longer than 2 weeks due to an illness, accident, or hospital admission; (3) someone who was chronically ill or disabled; and (4) someone for other reasons. Where 1 or more of these 4 situations applied, the respondent was identified as an informal caregiver (N = 4484). A follow-up written questionnaire on informal caregiving was then

administered in which 2813 respondents participated. Respondents for whom crucial information for this study was missing were removed, resulting in a final sample of 2485 informal caregivers.<sup>9</sup> For our analysis, we selected a sample of informal caregivers (family members, friends, neighbors) who were caring for community-dwelling older adults aged 60 years and older (n = 1267). Care recipients younger than 60 years (n = 1050) and older care recipients living in a nursing or residential care home (n = 168) were excluded from the sample (Figure 1).

## Measures

#### Informal Caregiver Outcomes

*Burden of care* was assessed using the 14-item Self-Perceived Pressure from Informal Care Scale<sup>9</sup> with items, such as "Generally speaking I felt very pressured because of the situation of my care recipient" and "I was too tired to do anything in my free time in the period that I was providing help." Responses were coded as 0 = disagree and 1 = (somewhat) agree. Item scores were added to produce a total score ranging from 0 (no burden) to 14 (heavy burden; *H* value = 0.87, Cronbach  $\alpha = .86$ ).

*Positive experiences with care* were assessed using the 6item Positive Experiences Scale (PES) to measure informal caregivers' intrinsic satisfaction and relational and social enhancement.<sup>10</sup> Examples of items are, "I felt closer to my care recipient during the period I was providing care" and "Looking after my care recipient gave me a good feeling." The reliability and scalability of the positive evaluation items were tested using the Mokken scale analysis and Cronbach  $\alpha$  and produced values that were above the required minimum (*H* value = 0.38, Cronbach  $\alpha$  = .70). Response categories were dichotomized into 0 = disagree and 1 = (somewhat) agree and were averaged to produce a total score (ranging from 0 to 1), with higher scores reflecting more positive experiences.

#### Stressors in the Care Context

The health status of the care recipient was reported by the informal caregiver. If interviewees reported that the care recipient had died during the 12 months preceding the interview, this was coded as provision of informal EOL care. The EOL care was thus defined as informal care provided in the last year of life. Care recipients were coded as having dementia if interviewees reported that the care need was caused by dementia and if they reported memory problems. Physical disabilities of care recipients were assessed using 13 items of basic and instrumental activities of daily life, such as being able to bathe, using the toilet without assistance, and performing household chores. Response options ranged from 1 (without difficulty) to 3 (only with help). Aggregate total scores ranged from 13 to 39, with higher scores representing more physical limitations.<sup>9</sup> Mokken scale analysis<sup>12</sup> was performed to test the homogeneity and reliability of the scale (*H* value = 0.66, Cronbach  $\alpha$  = .66). Care recipients' need for assistance and supervision was measured using 4 items: (1) supervision in household tasks, (2) supervision in financial administration, (3) being accompanied in social situations, and (4) being accompanied on visits to facilities such as hospitals, the local council, or the shops. Response options ranged from 1 (no help needed) to 3 (could not do without help), with a higher score indicating a greater need for accompaniment and supervision (Cronbach  $\alpha = .79$ ). Finally, caregivers were asked whether the care recipient could be left alone for longer than half an hour and whether they were bedridden (no, yes).

*Informal care provision* comprised (a) the total number of months for which informal care was provided; (b) the number of different types of caregiving, such as household tasks, personal care, nursing care, emotional support, administrative help, and accompanying on visits (range 1-5); and (c) the average number of hours spent on all types of caregiving per week. As some respondents reported caring for 24 hours a day, an average score of more than 112 hours per week was recoded as 112 hours, allowing for 8 hours' sleep per day.

## Characteristics of the Informal Caregiver

*Characteristics* included in the study were gender, age in years, relationship with the care recipient (spouse, adult child, other kin caregiver or nonkin caregiver), living with a partner, paid work, and attendance at religious services. This information was obtained in the questionnaire using direct questions, for example, "Did you share a residence with the care recipient

while providing informal care?" (no, yes), "Did you perform paid work in the past 12 months?" (no, yes), and "Do you attend religious services?" (no, yes).

## Social Resources

*Hours of support* comprised (1) the number of other informal caregivers involved, (2) the average number of hours of care provided per week by 3 other informal caregivers, (3) the average number of care hours per week provided by professional (paid) caregivers, and (4) the average number of hours of care per week provided by volunteers (ie, unpaid caregivers not in a social relationship with the care recipient and involved with a voluntary care organization).

Mobilization of support was measured using 6 dichotomized items referring to asking others for help, such as "I don't feel able to ask relatives or friends to help with providing the care" (0 = disagree, 1 = agree). Higher total scores indicated less willingness to ask for help (Cronbach  $\alpha = .73$ ).<sup>9</sup>

Evaluation of support was assessed by respondents rating their disagreements with other informal caregivers on 4 themes (type of care, frequency of care, distribution of tasks, and admission of potential care recipients to a nursing home). The responses were dichotomized to "1" when disagreements were reported on at least 1 item and "0" when no disagreements were reported.<sup>13</sup> Respondents also rated their unmet needs for informal caregiver support services provided by the municipality using 12 items (8 items on the need for information on informal caregiving and the care recipients' disease and 4 items on respite care), whether they needed such services (no, yes) and whether they used these services (no, yes). The total scores were combined and dichotomized into "1" where there was a need but no use of at least 1 informal caregivers' service, and "0" for no unmet need for any of the services. Unmet needs were reported separately for "information and advice" and "respite care."

## Procedure

To assess differences in caregiver outcomes (ie, burden of care and positive experiences) and all independent variables, 4 subgroups of care recipients were created: (1) dementia care at EOL, (2) dementia care not at EOL, (3) EOL care without dementia, and (4) no dementia or EOL care. We then performed descriptive analyses (mean, standard deviation) and analysis of variance to compare the subgroup means in Stata (version 18). As the first group only contained 41 respondents, we tested whether group comparisons had enough power to produce meaningful results (Table 1). The power for subgroup providing EOL care in dementia was 0.75 for the analyses using burden of care and 0.94 for the analyses using positive experiences of care. For the other subgroups, the power was 1.00 for both outcomes. Associations with the independent variables and the caregiver outcomes in the 4 subgroups were assessed in multivariable linear regression models developed using structural equation modeling with maximum probability of missing variables. First, unadjusted differences of the 2 outcome measures

Table 1. Comparison of the 4 Groups of Informal Care Recipients and Caregivers.

	EOL Care				
	Dementia	Nondementia	Dementia	Nondementia (Regular Care)	P Levels
 N (%)	41 (3%)	174 (14%)	215 (18%)	815 (65%)	
Informal caregivers' outcomes	. ,	. ,	. ,		
Emotional burden of care, mean (SD), range 0-14	5.1 (4.5)	4.6 (3.4)	4.7 (4.0)	3.6 (3.7)	<.00
Positive experiences, mean (SD), range 0-1	0.49 (0.34)	0.65 (0.28)	0.44 (0.30)	0.52 (0.30)	<.00
Health status care recipient	· · · ·	( )	( )	× ,	
Activities of daily living, mean (SD), range 13-39	33.8 (5.2)	33.7 (5.2)	29.2 (6.6)	29.2 (6.4)	<.00
Need for supervision, mean (SD), range 1-3	2.8 (0.31)	2.4 (0.52)	2.6 (0.49)	2.3 (0.55)	<.00
Can stay alone for longer than half an hour, %	62	72	86	94	<.00
Bedridden, %	47	75	17	39	<.00
Care provision		,,,	.,		
Number of years of care, mean (SD)	3.5 (4.5)	3.1 (4.4)	5.2 (5.5)	5.0 (6.6)	<.00
Number of hours care per week, mean (SD)	20.4 (30.7)	29.3 (31.4)	17.9 (26.5)	19.1 (26.7)	.00° .05ª
Number of tasks, mean (SD)	4.1 (1.4)	3.8 (1.4)	4.1 (1.2)	3.6 (1.3)	<.00
Caregiver characteristics	ч. і (1. <i>ч)</i>	3.0 (1.1)	ч.т (т. <u>с</u> )	5.6 (1.5)	<b>00</b>
Female, %	70	65	64	65	.95
Age, mean (SD)	52.4 (8.2)	56.1 (12.6)	52.5 (11.6)	53.7 (12.7)	.13
Living together, %	79 (0	60	69	70	<.00
Working, %	69	47	64	52	.
Religiously involved, %	40	54	43	51	.18
Relationship with care recipient, %	-				
Spouse	0	16	8	17	.02
Adult child	85	60	76	60	
Other family	5	7	7	7	
Nonkin	10	18	10	17	
Care recipients' characteristics					
Female, %	42	55	64	71	<.00
Age, mean (SD)	84. I	78.8	81.1	76.7	<.00
Living arrangement, %					
Living alone	57	87	38	78	<.00
Living together	27	23	25	18	
Other	16	22	37	35	
Educational level					
Low	41	55	53	65	<.00
Average	33	25	33	24	
High	26	20	14	11	
Support characteristics					
Not seeking support, mean (SD), range 0-6	0.84 (1.4)	1.2 (1.6)	0.98 (1.4)	1.3 (1.5)	.05
Hours per week professional care, mean (SD)	11.9 (10.8)	8.5 (16.0)	5.8 (9.7)	3.0 (5.2)	<.00
Hours per week other informal caregivers, mean (SD)	· ,	29.4 (48.3)	15.0 (26.8)	8.1 (20.2)	<.00 <.00
Hours per week volunteers, mean (SD)	1.1 (4.1)	1.5 (8.3)	0.25 (2.2)	0.47 (2.0)	00 .1
	3.1 (2.2)	. ,		2.5 (1.7)	.1
Number of other informal caregivers, mean (SD)	23	3.1 (2.0)	2.6 (1.8) 20		
Unmet needs information and advice, % yes		14	20	18	.45
Unmet needs respite care, % yes	26	9	12		.12
Disagreements with other informal caregivers, % yes	23	10	23	7	<.00

Abbreviations: EOL, end of life; SD, standard deviation.

among the 4 subgroups were assessed (model 1 in Tables 1 and 2). Subsequently, for each set of variables (eg, care stressors, characteristics of the informal caregiver, social resources), we separately assessed whether they explained differences in the 2 main outcomes in the 4 subgroups (models 2-4 in Tables 1 and 2). Lastly, we assessed differences between the 4 subgroups while adjusting for all 3 sets of variables for each outcome. The subgroup of care recipients who received neither dementia nor EOL care (regular care) served as the reference category.

## Results

## Description of the Sample by Dementia and EOL Care

Overall, 17% of the informal caregivers provided EOL care (Table 1); 14% provided EOL care to nondementia care recipients (n = 174) and 3% to older adults with dementia (n = 41). The majority of the informal caregivers (83%) provided non-EOL care, of whom 18% provided care to older adults with dementia (n = 215) and 65% provided care to nondementia older

	Model I	Model 2	Model 3	Model 4	Model 5
Four subgroups of care recipients					
Dementia and EOL care	1.46 <sup>a,b</sup>	0.62	۱.50 <sup>b</sup>	1.04	0.37
Dementia	0.86 <sup>b</sup>	0.35	0.84 <sup>c</sup>	0.71 <sup>b</sup>	0.37
EOL care	0.82 <sup>b</sup>	0.11	1.04 <sup>c</sup>	0.65 <sup>b</sup>	0.26
Regular care (nondementia, non-EOL; reference category)					
Care context					
Activities of daily living		-0.02			-0.02
Need for supervision		0.36			0.36
Capability of being alone for longer than half an hour		-0.79 <sup>b</sup>			-0.84 <sup>b</sup>
Bedridden		0.63 <sup>c</sup>			0.70 <sup>c</sup>
Number of years involved in care		0.01 <sup>d</sup>			0.01 <sup>d</sup>
Number of care tasks		0.92 <sup>d</sup>			0.63 <sup>d</sup>
Hours of care per week		0.03			0.02 <sup>d</sup>
Characteristics of the informal caregiver					
Female			1.11 <sup>d</sup>		0.86 <sup>d</sup>
Age			-0.01		0.00
Living together			0.04		0.24
Working			-0.30		0.25
Religious involvement			-0.18		0.05
Relationship with the care recipient					
Spouse			3.48 <sup>d</sup>		0.19
Parents			2.34 <sup>d</sup>		0.86 <sup>d</sup>
Other family			0.50		-0.16
Nonkin (reference category)					
Social support characteristics					
Hours per week professional care				0.02 <sup>b</sup>	0.01
Hours per week other informal caregivers				0.01 <sup>c</sup>	-0.00
Hours per week volunteers				-0.01	-0.00
Number of other informal caregivers				-0.20 <sup>c</sup>	-0.16 <sup>c</sup>
Disagreements with other informal caregivers				1.32 <sup>d</sup>	1.17 <sup>d</sup>
Not seeking support				0.75 <sup>d</sup>	0.62 <sup>d</sup>
Unmet needs respite care				1.74 <sup>d</sup>	1.06 <sup>c</sup>
Unmet needs information and advice				1.55 <sup>d</sup>	1.32 <sup>d</sup>
$R^2$	0.01	0.27	0.12	0.23	0.42

Abbreviation: EOL, end of life. <sup>a</sup>Unstandardized  $\beta$  coefficients. <sup>b</sup>P < .05.

<sup>d</sup>P < .001.

adults (further referred to as "regular care"; n = 815). No statistically significant correlation was found between burden of care and positive experiences of care (r = -0.01, P = .60). Caregivers who provided regular care reported the lowest levels of caregiver burden, whereas those providing EOL care involving dementia reported the highest levels of burden. Providing informal care at EOL without dementia produced the most positive experiences, while the fewest positive experiences were reported by those providing non-EOL dementia care.

The 4 groups differed with respect to the stressors in the care context: the degree of impairment of the care recipients and features of the care provision (Table 1). Health status, hours, duration, and type of caregiving differed the most between the 4 subgroups, with care recipients receiving EOL care having more physical limitations, more dependency on the informal caregiver, and higher care intensity (especially in the EOL with dementia group). Care recipients with dementia

were significantly less often bedridden than care receivers without dementia, both at EOL and non-EOL, and between 38% (non-EOL) and 57% (EOL) were still living alone. However, the duration of care provision was found to be lower among the EOL caregivers relative to non-EOL caregivers. Additionally, differences were found with respect to the resources in the social context: Caregivers providing EOL care reported more hours of help from informal and formal helpers, both in the dementia and nondementia subgroups, and dementia caregivers relative to nondementia caregivers.

#### Informal Caregiver Outcomes and Associated Factors

Table 2 shows the results of the multivariable regression analyses on caregiver burden. Providing EOL care to a person with dementia showed the largest effect on caregiver

<sup>&</sup>lt;sup>c</sup>P < . 01.

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	Model I	Model 2	Model 3	Model 4	Model 5
Four subgroups of care recipients					
Dementia and EOL care	$-0.59^{a}$	-0.57	-0.29	<b>-0.54</b>	-0.45
Dementia	-0.81 <sup>b</sup>	-0.68 <sup>b</sup>	−0.6 l <sup>ь</sup>	−0.73 <sup>b</sup>	-0.56 <sup>c</sup>
EOL care	0.94 <sup>b</sup>	0.83 <sup>b</sup>	0.87 <sup>b</sup>	0.85 <sup>b</sup>	0.56 <sup>d</sup>
Regular care (nondementia, non-EOL; reference category)					
Care context					
Activities of daily living		0.01			-0.00
Need for supervision		-0.30			-0.15
Capability of being alone for longer than half an hour		-0.59 <sup>b</sup>			-0.44 <sup>d</sup>
Bedridden		0.03			0.16
Number of years involved in care		0.04 <sup>b</sup>			0.04 <sup>b</sup>
Number of care tasks		-0.05			0.09
Hours of care per week		0.01°			0.01
Characteristics of the informal caregiver					
Female			0.38 <sup>d</sup>		0.35 <sup>d</sup>
Age			$-0.02^{d}$		-0.02 <sup>d</sup>
Living together			0.08		0.05
Working			-0.62 <sup>b</sup>		-0.55 <sup>c</sup>
Religious involvement			0.49 <sup>b</sup>		0.52 <sup>b</sup>
Relationship with the care recipient					
Spouse			-0.16		-0.68 <sup>d</sup>
Parents			-0.89 <sup>b</sup>		-1.11 <sup>b</sup>
Other family			-0.69 <sup>d</sup>		-0.75 <sup>d</sup>
Nonkin (reference category)					
Support characteristics					
Not seeking support				0.11 <sup>d</sup>	0.02
Hours per week professional care				0.00	0.01
Hours per week other informal caregivers				0.00	0.00
Hours per week volunteers				0.01	-0.00
Number of other informal caregivers				0.07	0.07
Disagreements with other informal caregivers				-0.47 <sup>d</sup>	-0.44 <sup>d</sup>
Unmet needs respite care				-0.23	-0.15
Unmet needs information and advice				-0.27	-0.21
$R^2$	0.05	0.08	0.11	0.07	0.15

Table 3. Multivariable Analyses of Factors Associated With Informal Caregivers' Positive Experiences With Care (N = 1235).

Abbreviation: EOL, end of life. <sup>a</sup>Unstandardized  $\beta$  coefficients. <sup>b</sup>P <.001. <sup>c</sup>P <.01.

burden, followed by providing non-EOL dementia care, and nondementia EOL care, compared with regular care (Table 2, model 1). After including variables concerning health status and care provision, these differences were no longer statistically significant (model 2). The effects remained significant when only caregiver characteristics were included (model 3), and the effect of providing EOL dementia care weakened to nonsignificant when only the support variables were included (model 4). The full model (model 5) showed no effects of EOL and/or dementia care on burden; this can be attributed to differences in health status, care provision, and assistance from formal and informal caregivers. It also explained 42% of the variance in caregiver burden, which was largely due to the care recipient being more dependent, a higher intensity and longer duration of care, the caregiver being female, providing care to parents, fewer other

informal caregivers being present, higher unmet needs, and disagreements with other caregivers.

As regard positive experiences, in the unadjusted analysis, informal caregivers providing non-EOL dementia care reported significantly fewer positive experiences compared to regular care, while informal caregivers providing nondementia EOL care reported more positive experiences compared to those providing regular care (Table 3, model 1). These differences remained significant after adjustment of the analysis, which means they were not explained by the stressors in the care context, characteristics of the informal caregiver, or social resources. The full model (model 5) explained 15% of the variation in positive evaluations; this was largely due to caregiver characteristics, especially being female, not working, religious, and being a nonkin caregiver. Having disagreements with other caregivers significantly lowered positive

<sup>&</sup>lt;sup>d</sup>P < .05.

evaluations, but health status, care provision, and presence of support from others had little effect.

## Discussion

The aim of this study was to assess the association between proximity to EOL and informal caregivers' burden of care and positive experiences, with and without dementia, and to explain differences in outcomes. To summarize, dementia caregivers, particularly at EOL, reported higher burden of care and fewer positive experiences of care, but only differences in burden were explained by the severity of the stressors and lack of resources studied. Differences in positive experiences of care could not be explained by the stressors and resources in this study.

As far as we are aware, the positive outcomes at EOL, with or without dementia, have not been studied before; Ornstein et al<sup>14</sup> and Vick et al,<sup>15</sup> for example, used negative outcomes only when comparing EOL and non-EOL caregiver outcomes within dementia and other disease groups and reported increased caregiver strain toward EOL in dementia. Our study highlights less positive experiences associated with informal caregiving with dementia at EOL and non-EOL compared with informal caregiving without dementia. This difference could be explained in part by dementia caregivers reporting more disagreements among informal caregivers. Indeed, previous research has reported the impact on burden of care of negative interactions among informal caregivers to be greater than that of positive interactions.<sup>13</sup> Additionally, it has been reported previously that relational aspects assessed on the PES (such as being appreciated by the care recipient, receiving something in return from the care recipient) are less applicable to informal caregivers of people with dementia, which may explain their relatively low score on the PES.<sup>16</sup> Nevertheless, since caregiver burden and positive experiences of care are different concepts, it is unknown whether the use of Pearlin stress-process theory<sup>10</sup> provided enough information to explain also positive experiences of care. It may be that dementia, a disease with farreaching consequences for the personality and behavior of those affected, negatively impacts the intrinsic motivations to provide and rewards from providing long-lasting informal care and that informal caregivers' attitudes and values regarding a "good death" may be conflicting with the reality with dementia. Future research should explore the concept more thoroughly in the context of dementia care, enabling the expansion of its theoretical basis and the construction of a reliable measure to assess positive experiences of care among informal caregivers.

Since palliative care aims to add life to days that are limited in number,<sup>17</sup> both for the patient and the informal caregiver, generalist and specialist palliative caregivers have the means to increase positive experiences of care in dementia up to the moment of death. For example, adequate communication about dementia and its consequences for everyone involved should include advanced decision-making in the early stages of the disease. This entails adequate and frequent information about the disease and its treatment options, and repeating communication about (changing) life goals and wishes regarding care before and during death, from the perspective of both the patient and the informal caregiver. Informal care networks could also be supported, for example, by appointing care network managers,<sup>13</sup> so that the benefits of caring together outweigh the risks. Finally, caregiver support services need to support informal caregivers in finding alternative ways to cope with the disease and (re)connecting with the person with dementia, tailored to their individual needs.

This study has some limitations. First, the subgroup representing informal caregivers providing EOL care to older adults living at home with dementia was small, but the power was sufficient to produce meaningful results. The majority of older people with dementia die in residential care.<sup>18</sup> However, cutbacks in residential care in the Netherlands may increase the number of people with dementia dying at home, and our findings show that their informal caregivers need a lot of support from palliative care teams. Second, we defined EOL care as care provided to people who had died in the 12 months preceding the interview. Care recipients who died shortly after the interview were not included in the EOL group, which implies that the differences in outcomes between EOL and non-EOL care may have been underestimated. In addition, a diagnosis of dementia was not confirmed using evidence-based diagnostic tools, but dementia is generally underdiagnosed in the community and we relied on information provided by the informal caregiver. Finally, the data were collected retrospectively, potentially resulting in inaccurate reporting of care outcomes. However, the way in which memories live on in caregivers is itself an important outcome. Also, the study did not include EOL-specific questions, such as dilemmas regarding treatment, transfers to hospital or a hospice, and the criteria determining a "good death." Although the caregiver experience in the final year of life was not specified in the survey, differences between the care context at EOL and non-EOL were considerable and clearly added to our understanding of the higher caregiver burden in EOL care. Longitudinal study designs with frequent data collection points, including qualitative data, might offer a useful means of assessing changes in informal EOL care outcomes over time.

Despite these limitations, and unlike most of the literature on informal EOL care, this study is unique in focusing on informal EOL care for community-dwelling older adults and comparing caregiving outcomes across relevant patient groups. This study may also provide guidance for practice and future research aimed at boosting palliative care at home for the growing group of older adults with life-limiting diseases and their informal caregivers.

#### **Authors' Note**

J. A. Boogaard, J. T. van der Steen, A. de Boer, and M. I. Broese van Groenou designed the study and formulated the research questions. J. A. Boogaard analyzed the data. J. A. Boogaard, J. T. van der Steen, and M. I. Broese van Groenou wrote the article. A. de Boer assisted with the data analysis and writing the article.

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