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The end of life: informal care for dying older people and its relationship to place of death

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Objective: This study examined the features of informal end-of-life care of older people living in the community and the association between informal care characteristics and dying at home. **Methods:** Retrospective data were obtained from interviews and self-administered questionnaires of 56 persons who had been primary caregivers of older relatives in the last three months of their lives. **Results:** Results showed that informal caregivers of terminally ill older people living in the community provided a considerable amount of personal, household, and management care. Secondary informal caregivers and formal caregivers assisted resident primary caregivers less often than nonresident primary caregivers. Primary caregivers who felt less burdened, who gave personal care more intensively, and/or who were assisted by secondary caregivers, were more likely to provide informal end-of-life care at home until the time of death. **Conclusions:** Our study showed that informal care at the end of life of older people living in the community is complex, since the care required is considerable and highly varied, and involves assistance from secondary informal caregivers, formal home caregivers as well as institutional care. Burden of informal care is one of the most important factors associated with home death. More attention is needed to help ease the burden on informal caregivers, specifically with regard to resident caregivers and spouses. Since these resident caregivers were disadvantaged in several respects (i.e., health, income, assistance from other carers) compared to nonresident caregivers, interventions by formal caregivers should also be directed towards these persons, enabling them to bear the burden of end-of-life care. *Palliative Medicine* 2004; **18**: 468–477

Key words: end of life; formal care; informal care; place of death; secondary informal caregivers

Introduction

The chance that older people will spend their final year of life in poor health has increased due to the growing life expectancy. The process of dying, therefore, may now more often be a prolonged stage in which extensive and complex care is needed.^{1,2} Because terminally ill older persons tend to prefer being cared for in their own home as opposed to in some health care institution, informal caregivers may now have to provide end-of-life care more often and for a longer period than was previously the case.³ There is also evidence to suggest that, although the majority of people in the Netherlands

die in hospital, the process of dying that precedes this occurs typically at home, where family members provide care.⁴ In addition, due to reduced health care budgets in the past ten years, formal home care is allocated only if the need for care is very high and/or informal carers are no longer able to perform the required care activities. Studies indicate that only one in five chronically ill or disabled persons makes use of professional care resources.⁵ Government policies are tending to shift their focus from professional to informal care, thereby resulting in an increase in pressure on informal caregivers due to substitution policies.^{6,7} Informal caregivers, therefore, make up a substantial part of the Dutch care system for dying older people.⁸ Without the support of these caregivers – usually family members – it would be impossible for many dying older persons to remain at home.⁴

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In research, however, little exclusive attention has been paid to informal end-of-life care and its relationship to place of death. End-of-life studies are mainly focused on professional palliative care for terminally ill patients and place of death.^{9–11} In their review, Grande *et al.* for example identified only a few characteristics of informal care related to home death: dying at home was more common among persons with female caregivers, and among those who received care for a brief period.¹¹

In the few studies that exist on informal end-of-life caregiving, it is suggested that taking care of a dying loved one can be a very complex, often long-term, life event,² which may have significant impact on the physical, mental, and social functioning of the informal caregivers.¹² Additionally, they are often confronted with a considerable need for nursing and personal care as well as household tasks.¹³ Emanuel *et al.* show that although women provide the majority of this informal end-of-life care, when women themselves need care they receive less assistance from family members and friends than men do.¹⁴ These studies, however, are solely focused on the primary caregiver and have been performed only in selected populations, such as cancer patients, or patients already receiving formal care. We propose that it is important to explore the whole care network of which a dying older person living in the community is a part, since both the increased need for care at the end-of-life stage, and the greater claim on the primary caregiver's resources imply that primary informal caregivers may need, and actually make use of, more assistance from secondary informal caregivers, formal home care, and/or institutional care.^{15–18} In contrast to other end-of-life studies,^{1,2,12,14,19} we were able to gather data from a population-based sample that is unselected with respect to terminal conditions.

In this study we aim to extend the knowledge on three aspects of informal end-of-life care: (1) who provides care to dying older people living in the community, and what is the nature and extent of their caregiving activities; (2) to what degree do dying older people receive assistance from secondary informal and formal caregivers, and (3) what characteristics of informal care are associated with dying at home. We distinguish between resident and nonresident primary caregivers, since we assume that there are differences between these two groups with regard to the nature and intensity of the caregiving tasks.

Methods

Study sample

Data are derived from a study on 56 informal caregivers who provided care to independently living older adults in

the last three months of their lives. This study is part of the Longitudinal Aging Study Amsterdam (LASA), an ongoing study on physical, cognitive, emotional, and social functioning in older people in the Netherlands. The main LASA sample is derived from a large survey conducted in 11 communities in the Netherlands, varying in region (the north-eastern, southern and western parts of the country) and degree of urbanization (large cities and small villages). The LASA sample is considered to be representative for the Dutch population of older people.²⁰ Face-to-face interviews with relatives of 270 LASA respondents who died between 1996 and 1998, were held to acquire retrospective information about the health and wellbeing of older people in the last three months of their lives.²¹ In this paper the focus is on the selection of this sample of 270 relatives, namely those relatives who provided informal caregiving to LASA respondents living independently in the last three months of their lives. Since 100 respondents did not live independently at home three months before dying, they were excluded. Of the remaining 170 LASA respondents, 78 had an informal caregiver who matched with our criteria: providing personal care when sharing the same household or providing household and/or personal care when living outside of the household of the care receiver. We used this distinction because we presumed that it is difficult for resident caregivers to distinguish normal household tasks from extra household tasks related to caregiving.¹⁵ Of these 78 relatives, 56 persons completed the written questionnaire on aspects of caregiving. The other 22 relatives did not fill in the questionnaire completely, or refused to fill it in. The mean time interval between death and data collection was two years and two months (range: 4 months–3 years and 8 months).

Measurements

Care receivers. Data on the care receivers were obtained from the face-to-face interviews with the relatives of the deceased LASA respondents.²² Socio-demographic variables of the care receivers were age at time of death, sex, and marital status. Health characteristics of the care receivers were functional limitations, chronic diseases, institutionalization (hospital, residential home, and nursing home) and cause of death. Functional limitations of the care receivers at three months and three days, respectively before death were assessed using a questionnaire that included the following activities:²³ ability to walk up and down stairs, to dress oneself, to sit on and rise from a chair, to cut one's own toenails, to walk outside the house for five minutes, and to use their own means of transport or public transport. The scale total ranged from zero (no limitations for all six activities) to 24 (totally limited

for all six activities). (Three months: Cronbach's $\alpha = 0.90$; three days: Cronbach's $\alpha = 0.71$; $n = 50$.)

Information about chronic diseases was focused on the following seven chronic diseases: chronic nonspecific lung disease, cardiac disease, peripheral atherosclerosis, cerebrovascular accident, diabetes mellitus, arthritis and malignant neoplasms. Responses were summed to a score: 0 'no chronic diseases'; 1 'one chronic disease'; 2 'two chronic diseases'; 3 'three chronic diseases'; and 4 'four or more chronic diseases'. Finally, relatives reported the most important cause of death, which was dichotomized into 'died of cancer no/yes'.

Informal caregivers. Sociodemographic characteristics of the primary informal caregiver were age, sex, marital status, level of education in four categories (1 = 5–6 years, 2 = 9 years, 3 = 10–11 years, and 4 = 12 years or more), net monthly income level in four categories (1 = €499–907, 2 = €908–1134, 3 = €1135–1588, and 4 = €1589 or more), type of relationship with the care receiver, geographic proximity, and the number of other responsibilities in addition to the care for the dying relative (including: own household, paid job, care for another person, voluntary work, study, ranging from zero to three or more).

Informal care tasks were categorized into three groups: personal care (10 tasks, such as helping with washing/bathing, dressing, giving medication), household care (13 tasks, such as running errands, cleaning, cooking), and management care (six tasks, such as transportation, visiting the doctor, financial help). For both personal and household care the amount of care per task was reported (0 = no help, 1 = helped sometimes, 2 = helped regularly). The intensity of total personal care ranged from zero to 20 (Cronbach's $\alpha = 0.86$, $n = 53$). Resident caregivers were not asked about household tasks, but reported whether their usual household care had changed in the last three months: no change, more care, less care. For the nonresident caregivers the intensity of household care ranged from zero to 26 (Cronbach's $\alpha = 0.92$, $n = 19$).

With respect to the availability of other caregivers, respondents indicated the number of different types of secondary informal caregivers (ranging from zero to ten) and formal caregivers (ranging from zero to five) who assisted them with personal and/or household care. One question was used to indicate the duration of informal care in years, recoded into: three months or less, three months to one year, and longer than one year. Caregiver burden was asked using the following question: 'How burdened did you feel in the last three months of... life?' Response categories were: (1) not or hardly burdened; (2) somewhat burdened; (3) moderately burdened; (4) heavily burdened.

Results

First we describe the demographic characteristics and health status of the care receivers. As shown in Table 1, care receivers were mostly male, and more than half of the care receivers shared the household with the primary caregiver. Care receivers with a resident caregiver were somewhat younger than those with a nonresident caregiver. Gender differences in the type of relationship with the informal caregiver showed that men received informal care mostly from their spouses ($n = 26$), whereas women obtained most informal care from their daughters or daughters-in-law ($n = 10$, $P < 0.05$).

The health status of the care receivers in the last three months of their lives is characterized by a considerable increase in functional limitations and multiple chronic diseases. At three days before death they were almost completely limited. The older people with a resident caregiver were more functionally limited than those with a nonresident caregiver. During the last three months more than half of the group of care receivers was institutionalized. In most cases, they were transferred to a hospital shortly before they died. The majority died in hospital and only a few returned to their homes, where they died. There were no significant differences in institutionalization between care receivers with a resident or a nonresident caregiver.

Twenty-seven care receivers died of cancer and 29 of other causes, such as cardiovascular diseases ($n = 12$) and respiratory diseases ($n = 3$).

The primary informal caregivers were predominantly female. When a spouse was available, she or he was the primary caregiver. Other primary caregivers were children ($n = 20$), daughters-in-law ($n = 3$), one sister, three friends, and one wife of a cousin. The resident caregivers were significantly older than the nonresident caregivers, and also reported lower income and educational levels than the nonresident caregivers.

Almost all caregivers lived close by. In addition to the 28 spouses, there were two children and one sister who shared the same house with the older person. Most of the nonresident informal caregivers lived within a travelling time of 15 minutes. The nonresident caregivers reported having significantly more responsibilities in addition to the care for the dying relative than resident caregivers, such as their own household ($n = 21$), and a paid job (part-time, $n = 15$; full-time, $n = 4$).

As shown in Table 2, most of the informal caregivers had been caregivers for a longer period of time and nearly half of them for over a year. The resident primary caregivers' time was taken up with informal care seven days per week, whereas nonresident caregivers provided care for an average of five days per week. The informal caregivers who provided assistance with personal care ($n = 48$) reported that they mostly helped with dressing

Table 1 Characteristics of the care receivers (CR) and primary caregivers: absolute numbers and means (*M*)

Care receivers	Resident	Nonresident	Total	P
<i>n</i>	31	25	56	
Age at time of death <i>M</i> (SD)	77.5 (7.0)	81.4 (7.3)	79.3 (7.4)	n.s. ^a
Sex				
Men	28	15	43	χ^2 [7.1]**
Women	3	10	13	
Marital status				
Not married	4	19	23	χ^2 [22.8] ***
Married	27	6	33	
Functional limitations <i>M</i> (SD)				
Three months before death	14.2 (7.9)	14.5 (6.8)	14.4 (7.4)	n.s.
Three days before death	23.6 (1.2)	22.1 (3.7)	22.9 (2.7)	<i>F</i> [4.7]*
Chronic diseases <i>M</i> (SD)				
Three months before death	2.4 (1.2)	2.3 (1.3)	2.3 (1.2)	n.s.
Type of informal caregiver				
Spouse/partner	28	0	28	χ^2 [45.4]***
Child (in-law)	2	21	23	
Other	1	4	5	
Institutionalisation and place of death				
No instit., died at home	13	12	25	n.s.
Instit., died at home	7	2	9	
Instit., died in institution	11	11	22	
Primary caregivers				
Age <i>M</i> (SD)	70.5 (9.2)	51.4 (12.7)	61.9 (14.4)	<i>F</i> [42.3]***
Sex				
Men	2	2	4	n.s.
Women	29	23	52	
Marital status				
Married to CR	28	0	28	χ^2 [46.4]***
Married	1	20	21	
Not married	2	5	7	
Geographic proximity ^b				
Resident	31	0	31	
Within 15 minutes	0	18	18	
> 15 minutes	0	7	7	
Education level <i>M</i> (SD) (range 1–4) (<i>n</i> = 55)	1.7 (1.0), <i>n</i> = 31	2.8 (0.8), <i>n</i> = 24	2.2 (1.0)	<i>F</i> [15.0]***
Income level <i>M</i> (SD) (range 1–4) (<i>n</i> = 50)	2.0 (1.0), <i>n</i> = 28	3.2 (0.7), <i>n</i> = 22	2.5 (1.1)	<i>F</i> [21.0]***
Other responsibilities <i>M</i> (SD) (range 0–3) (<i>n</i> = 52)	0.7 (0.5), <i>n</i> = 27	2.0 (0.7), <i>n</i> = 25	1.3 (0.9)	<i>F</i> [55.6]***

^aNot significant; ^bmaximum 60 minutes; **P* < 0.05; ***P* < 0.01; ****P* < 0.000.

(*n* = 34), getting in and out of bed (*n* = 31), with going to the toilet (*n* = 31) and with giving medication (*n* = 37). On average, the resident caregivers provided personal care more intensively than nonresident caregivers.

The household tasks that nonresident caregivers often provided were running errands (*n* = 21), washing dishes (*n* = 18), doing the laundry (*n* = 16) and odd jobs around the house (*n* = 16).

Many of the primary informal caregivers also carried out management tasks, such as visiting the doctor (*n* = 38), supervising (*n* = 21), filling in forms (*n* = 34), attending to financial affairs (*n* = 34), buying important things

(*n* = 41), and arranging and organizing care (*n* = 41). On average, they provided 3.7 (SD 1.8) management tasks (0–6 tasks). There were no differences between resident and nonresident caregivers in this respect.

Finally, we noted that more than half of the primary caregivers (Figure 1) assisted with all three types of care (*n* = 30): personal, household, and management care. Only five caregivers reported that they assisted with only one type of informal care.

As shown in Table 2, about half of the primary caregivers received a combination of secondary informal care and formal home care. A smaller number received

Table 2 Informal care characteristics

Caregivers	Resident	Nonresident	Total	P
<i>n</i>	31	25	56	
Duration of informal care				
< 3 months	10	4	14	n.s.
3 months–1 year	7	9	16	
> 1 year	14	12	26	
Days per week care in general <i>M</i> (SD) (<i>n</i> = 54)	7 (0.0), <i>n</i> = 31	5.0 (2.2), <i>n</i> = 23	6.1 (1.7)	<i>F</i> [27.8]***
Intensity of personal care <i>M</i> (SD) (<i>n</i> = 53) (range 0–20)	10.6 (4.8), <i>n</i> = 30	7.9 (6.6), <i>n</i> = 23	9.5 (5.7)	<i>F</i> [3.1]+
Intensity of household care <i>M</i> (SD) (<i>n</i> = 19) (range 0–26) ^a	13.3 (7.7)			
Assistance from others (<i>n</i> = 54)	3	0	3	χ^2 [10.35]*
No help from others				
Only formal help	7	4	11	
Only secondary informal help	10	3	13	
Combination	9	18	27	
Number of types of secondary caregivers <i>M</i> (SD)	1.4 (1.7)	3.3 (1.8)	2.3 (1.9)	<i>F</i> [15.5]***
Number of types of formal caregivers <i>M</i> (SD)	0.9 (1.0)	1.9 (1.0)	1.4 (1.1)	<i>F</i> [13.7]**
Caregiver burden <i>M</i> (SD) (<i>n</i> = 54)	2.2 (1.0), <i>n</i> = 29	2.2 (0.9), <i>n</i> = 25	2.2 (0.9)	n.s.

^aOnly available for nonresident caregivers; +*P* < 0.10; **P* < 0.05; ***P* < 0.01; ****P* < 0.000.

assistance from formal caregivers only, or from secondary caregivers only. Only three primary caregivers were sole providers of care. Resident primary caregivers received help from fewer types of secondary informal caregivers and from formal care than was the case for nonresident caregivers. Also, nonresident primary caregivers were assisted more often by a combination of secondary informal and formal caregivers than was the case for resident caregivers.

As shown in Table 2, there were, on average, no significant differences in perceived burden between resident and nonresident caregivers.

In order to examine which primary caregiver was able to provide informal care at home until death, we looked at characteristics of the care receiver, of the primary caregiver, and the care network surrounding the primary caregiver. The results (see Table 3) showed that dying at home was associated with a lower perceived burden of the primary caregivers than dying in an institution. Furthermore, primary caregivers who were more intensively involved with personal care were more likely to keep

providing informal care at home. Home death was also characterized by the presence of more (types of) secondary informal caregivers. Finally, it was shown that among older persons who died of cancer more home deaths were found than among noncancer patients. We have checked these univariate findings with a multivariate logistic regression analysis. The outcomes confirmed the univariate results: burden of informal care remained the strongest association with place of death. Informal caregivers who were able to keep providing informal end-of-life care at home were less burdened than informal caregivers whose care receivers died in an institution.

Discussion

In this study we explored informal end-of-life care and its relationship to place of death. We found indications that informal end-of-life care is characterized by specific features in which distinction is made between informal care in earlier stages of illness: amount, type, and variety of care tasks, assistance from secondary informal caregivers and use of formal home care, and transfers to institutional care. We showed that informal end-of-life care for older people living in the community is characterized by a considerable amount and variety of personal, household, and management care. Studies on informal care in earlier phases of illness showed that primary informal caregivers predominantly provide household care,^{15,24} but the high need for care at the end of life and the complex nature of this care seem to entail more complex and diverse informal caregiving tasks.

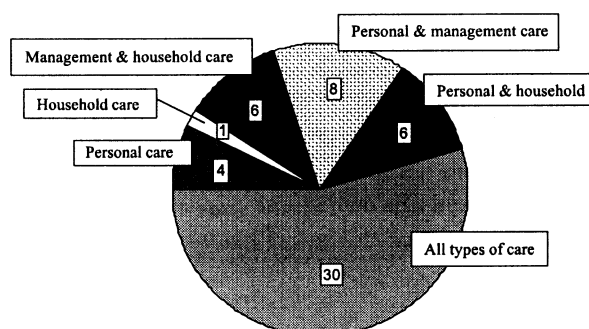


Figure 1 Types of informal care (*n* = 55).

Table 3 Univariate associations of characteristics of CR, primary caregivers and support system with place of death

Characteristics of the care receivers	Dying at home	Dying in an institution	Total	P
<i>n</i>	34	22	56	
Age at time of death <i>M</i> (SD)	78.5 (7.2)	80.5 (7.6)	79.3 (7.4)	n.s.
Sex				
Male	26	17	43	n.s.
Female	8	5	13	
Married				
No	12	11	23	n.s.
Yes	22	11	33	
Functional limitations <i>M</i> (SD)	14.2 (8.2)	14.7 (6.2)	14.4 (7.4)	n.s.
Number of chronic diseases <i>M</i> (SD)	2.3 (1.2)	2.5 (1.3)	2.3 (1.2)	n.s.
Cancer				
No	14	15	29	χ^2 [3.9] *
Yes	20	7	27	
Characteristics of the primary caregiver				
Age <i>M</i> (SD)	60.9 (14.7)	63.6 (14.2)	62.0 (14.4)	n.s.
Resident				
No	14	11	25	n.s.
Yes	20	11	31	
Marital status				
Married to CR	18	10	28	n.s.
Married	12	9	21	
Not married	4	3	7	
Education level <i>M</i> (SD) (<i>n</i> = 55)	2.0 (1.0), <i>n</i> = 34	2.5 (1.1), <i>n</i> = 21	2.2 (1.0)	n.s.
Income level <i>M</i> (SD) (<i>n</i> = 50)	2.6 (1.2), <i>n</i> = 30	2.4 (0.9), <i>n</i> = 20	2.5 (1.1)	n.s.
Number of other responsibilities <i>M</i> (SD) (<i>n</i> = 52)	1.3 (1.1), <i>n</i> = 32	1.4 (0.6), <i>n</i> = 20	1.3 (0.9)	n.s.
Duration of informal care				
< 3 months	8	6	14	n.s.
3 months–1 year	10	6	16	
> 1 year	16	10	26	
Days per week care in general <i>M</i> (SD) (<i>n</i> = 54)	6.3 (1.6), <i>n</i> = 33	5.9 (1.9), <i>n</i> = 21	6.1 (1.7)	n.s.
Intensity of personal care <i>M</i> (SD) (<i>n</i> = 53)	10.9 (5.8), <i>n</i> = 33	7.2 (4.8), <i>n</i> = 20	9.5 (5.7)	<i>F</i> [5.7]*
Caregiver burden <i>M</i> (SD) (<i>n</i> = 54)	1.9 (0.8), <i>n</i> = 33	2.7 (1.0), <i>n</i> = 21	2.2 (0.96)	<i>F</i> [8.7]**
Characteristics of the support system				
Number of types of secondary informal caregivers <i>M</i> (SD)	2.7 (2.0)	1.6 (1.9)	2.3 (1.9)	<i>F</i> [4.3]*
Number of types of formal caregivers <i>M</i> (SD)	1.5 (1.2)	1.1 (1.1)	1.4 (1.1)	n.s.

P* < 0.05; *P* < 0.01.

Contrary to other informal end-of-life care studies, which focused exclusively on the assistance provided by primary caregivers,^{1,2,12,14} we showed that informal end-of-life care was not only provided by a single primary caregiver, but that the primary caregiver was assisted by a number of secondary informal caregivers. These results confirm reports from informal care studies carried out in earlier stages of illness that older people receive assistance from a network of helpers.^{25,26} Furthermore, these studies showed that family caregivers do not often make use of formal care.^{15,16,27–29} We showed that not only did a considerable number of the primary caregivers receive assistance from formal home care, but they also had to

deal with admissions to institutional care. This indicates that informal care at the end of life is a special situation involving complex and demanding care tasks, which have to be carried out by a combination of formal and informal caregivers.

There are, however, concerns that formal care at home at the end of life is not provided in an adequate way.^{7,10} Professional caregivers are not used to focus on informal caregivers and their problems. The latter provide care without the health care system's formal acknowledgement of the pivotal nature of their role.³⁰ In a study by Addington-Hall *et al.*, many caregivers complained about the support from community services and the

care and information from hospitals.¹⁰ Van der Lyke argued that, when formal home care was present, the informal caregivers had a part of their autonomy taken from them, and their own home became part of the public area.⁷ More research is needed to understand the problems surrounding the involvement of professional care with informal end-of-life care.

Our results also underscore the differences between resident and nonresident caregivers, with the former being in a rather disadvantaged position. Being typically elderly spouses, they may be more vulnerable to health problems themselves because of their more advanced age. Research also shows that they face a higher mortality risk when they experience strain caused by informal care.³¹ We showed that resident caregivers provided personal care more intensively (seven days per week), had a smaller network of secondary and formal caregivers, and fewer resources with regard to health, income, and level of education. Despite the fact that we found no differences in perceived burden between resident and nonresident caregivers, the demanding task load and the fewer resources available to resident (spousal) caregivers, suggest that these persons run higher risks of becoming overburdened in the long run. On the other hand, the nonresident caregivers had to deal with more responsibilities in addition to the care for the dying older person, such as their own household or a job. The increasing need for (complex) care may threaten the effectiveness of the combination of these multiple responsibilities, and may have led these nonresident caregivers to call upon siblings or others to assist them in the provision of care for their relatives. As long as they are able to share the burden of end-of-life care with others, the nonresident caregivers may be able to continue their activities.

In this study, male care receivers were over-represented. What does this mean for women in need of care? Emanuel *et al.* argue that although women provide almost three quarters of all care for dying patients, when they themselves are dying, they must rely to a significantly greater extent on paid (or professional) help.¹⁴ Two factors may explain why male spouses play a much less significant role in informal caregiving than female spouses. The first explanation is that male spouses may be less able to provide care because they may be older and more disabled than female spouses. The other explanation may be that male spouses are less prepared to fulfil the social role function of informal caregiving.³² It has been argued that it is difficult to disentangle the spousal issue from the gender issue in assessing spousal caregiving.^{33,34} 'For example, if older married women are more likely to report formal sources of care than their male counterparts, one cannot know if this results from frail women needing more formal care or from male spousal caregivers needing more assistance in providing that care' (p. 236).³⁴

The last part of our study concerned informal care characteristics associated with dying at home. Berger *et al.* suggest that patients with informal caregivers or good family support are more likely to die at home than in hospital.³⁵ In our sample, of which a considerable part of the informal care receivers did not die at home, we were able to look in detail at differences between home deaths and institutional deaths, focusing on care receivers as well as on care providers. Perceived burden of informal care seemed to be the most significant factor. The primary caregivers of care receivers who died in an institution felt more burdened than those who took care of someone who died at home, although the care load (intensity of personal care) was lighter. Notwithstanding the fact that a longitudinal study or an intervention study is needed to test for causality, we suggest that institutional admissions before death are strongly associated with caregiver burden. This result supports other studies on predictors of institutionalization suggesting that excessive strain on informal caregivers is a common reason for older people to be admitted to a hospital.^{36,37} On the other hand, it may also be possible that informal caregivers feel more burdened because of stressors common to admission. Caregivers, for example, may experience feelings of guilt or failure because they had to hand over their role as primary care provider to institutional caregivers.³⁸ However, following admission, caregivers continue to provide care and remain committed to their relatives, although their tasks change.³⁹ Placement, then, shifts rather than eliminates the caregiver burden.⁴⁰ Caregivers also play an important role after admission in representing their relatives when difficult decisions must be taken regarding treatment. According to Pot, family caregivers experience new stressors and strains after institutionalisation.³⁹ For example, interactions with nursing staff may be stressful, because nurses will provide care in a different way or because family caregivers start feeling worthless. Gilmour suggests that formal caregivers, with respect to family caregivers, need to position themselves in secondary and supporting caregiving roles.⁴¹ Furthermore, they need to acknowledge the family caregiver as the primary caregiver, and make use of their in-depth and intimate knowledge of the needs of their relative to contribute to the care programme within the institutional setting. Intervention programmes need to be developed to prevent excessive strain from informal end-of-life care and thereby offer the choice of dying at home to a higher number of older persons. These programmes should take the above-mentioned complexities into account. A case-control or intervention study is needed to test whether informal care is causally related to people dying in their own home.

Although we did not ask the primary caregivers' perspectives on place of death, research indicates that

bereaved informal carers are more satisfied if the patient died at home as opposed to in hospital.^{4,9} However, the idea of dying at home may also be a little idealized. In some cases, when health care demands are too high, admission to a health care facility may be a better solution for both the patient and the informal caregiver.⁴² Future research should identify the informal caregivers' preferences regarding place of death.

Our study also highlights the importance of the availability of secondary informal caregivers to increase the feasibility of dying at home. As we showed that resident and thus older primary caregivers (mostly female spouses) had fewer secondary and formal caregivers available, these spousal primary caregivers are an appropriate target for intervention. Because they are more vulnerable to health problems considering their more advanced age, they run the risk of not being able to continue providing informal care at home through to the end.

In addition, caregivers who provided personal care more intensively without feeling more burdened were more likely to provide informal care at home until the time of death. This result is consistent with evidence from research focusing on predictors of institutionalization, which showed that patients were far less likely to be institutionalized when family members provided overnight and personal (ADL) care.³⁶ A possible intervention to prevent older people from dying in institutions may be to teach personal care skills to informal caregivers.

Cancer can be considered to be different from other terminal diseases. Seale argues that those dying of cancer are 'advantaged'.⁶ Many medical and nursing efforts in providing new approaches to end-of-life care are focused on cancer patients. Furthermore, their illness tends to be of shorter duration, if more intensely distressing, and, because of their younger age, cancer patients are more likely to have relatives available to help and to be there at the time of death.⁶ It may also be that cancer patients are 'advantaged' with regard to place of death. We found more home deaths among cancer patients than among noncancer patients. This may be explained by the shorter duration of the illness and the impact on informal caregiving burden. Or perhaps physicians are more comfortable viewing patients with cancer as dying than patients with other illnesses.¹⁴ Therefore they may send cancer patients home sooner than patients with other illnesses that are less predictable.

In interpreting the results, some limitations of this study have to be taken into account. One limitation of this study is that the sample is small and selective. It may not be considered fully representative for the informal home care situation in the general older population. The identification of the actual primary informal caregiver through relatives of the deceased was not optimal in some cases. Persons who did not consider themselves primary caregivers but did provide household or personal care

may not have been included. As a result, we may have underestimated the provision of personal care at the end of life. A second limitation is that we collected data retrospectively after the death of the LASA respondent. Retrospective questions can influence the data quality in a negative way. Research, however, showed that the quality of retrospective data is higher when the time interval between the event asked about and the moment of interviewing is short, when the recall period is short and when the event is salient.⁴³ Although the recall period was relatively long for some respondents, we feel that we can safely assume that end-of-life care for a relative is sufficiently salient to expect reliable information.

A third limitation is the fact that we use proxy information for the assessment of chronic diseases, functional limitations, and underlying cause of death. Klinkenberg *et al.* show, from results of another side study of the same LASA cohort, that after-death reports of significant others are comparable to reports of physicians with respect to malignant neoplasms, chronic nonspecific lung disease, diabetes mellitus and cerebrovascular accident.⁴⁴ However, the presence of rheumatoid arthritis, osteoarthritis and arteriosclerotic disease might be over-reported by significant others (results regarding cardiac disease were inconclusive).

Functional limitations were measured by questions concerning concrete and observable activities of daily living, which helps to achieve a better judgement from significant others.⁴⁵ With respect to underlying cause of death, the cancer/noncancer dichotomy is proven to be highly concordant with the information on the death certificates.

It is noticeable that we have no information about dementia in our study sample. Due to the longitudinal design and the intensive face-to-face interviews required for the LASA study, cognitively impaired respondents are likely to drop out earlier from this study and will thus be under-represented in our sample. The demands placed on caregivers of dementia patients differ to a large degree from the demands placed on caregivers of somatic patients. As cognitive impairment (not only from dementia) is common in the last phase of life,⁴⁶ it is important to incorporate this in future research into informal end-of-life care.

Conclusion

In a recent special issue on end-of-life care, it was suggested that more research on families who are involved with end-of-life caregiving is needed.⁴⁷ Our study showed that informal care at the end of life of older people living in the community is complex, since it requires a large amount and variety of care, and assistance from secondary informal caregivers, formal

home caregivers, as well as institutional care. The perceived burden of informal care is strongly associated with home deaths. Some informal end-of-life caregivers, such as residents (mostly spouses), older caregivers, and caregivers with a low income, may run higher risks of encountering problems of burden and health as a result of having less access to secondary informal and formal caregivers. This network of secondary informal and formal caregivers, however, is important for end-of-life care, as it may increase the possibility to die at home. These results draw attention to the interface between formal and informal care providers at home. To increase the opportunity for older people to die at home, more research is needed that identifies conditions under which formal caregivers may optimise informal end-of-life care, and reduce the perceived burden of informal end-of-life caregiving.

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