

End-of-Life Care

Findings From a National Survey of Informal Caregivers

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Background: Family and friends are thought to be the predominant providers of end-of-life care, although nationally representative data on this topic have been lacking.

Methods: This study draws from the 1999 National Long-Term Care Survey and its Informal Caregivers Survey to characterize primary informal caregivers' experiences providing end-of-life care to chronically disabled community-dwelling older adults. Study participants were 1149 primary informal caregivers, stratified by care recipients' survival or death during the following 12 months.

Results: An estimated 11.2% of the chronically disabled community-dwelling older adults died within 1 year of being interviewed. Among persons who died, 72.3% were receiving help from an informal caregiver at the time of the interview. End-of-life primary informal caregivers helped an average of 43 hours per week, 84.4% provided daily assistance, and caregiver support services were

infrequently used (ie, respite care and support groups were used by less than 5% of caregivers). While end-of-life caregivers reported significant emotional (28.9%), physical (18.4%), and financial (14.0%) strains, more than two thirds endorsed personal rewards related to their helping role. Compared with primary informal caregivers of persons who survived the following 12 months, end-of-life caregivers provided significantly higher levels of assistance and reported more challenges and strains, but they were no less likely to endorse rewards related to their helping role.

Conclusions: End-of-life caregivers provide frequent and intense assistance with few supportive services. These data underscore the relevance of families to end-of-life care, and the potential benefit of better integrating families in patient care.

Arch Intern Med. 2007;167:40-46

FAMILY AND FRIENDS ARE THE predominant providers of both long-term¹ and end-of-life care.^{2,3} Several studies have documented high levels of assistance provided by family at the end of life,^{2,4,5} as well as accompanying emotional, physical, and financial strains associated with providing this help.⁴⁻⁸ This body of work collectively indicates that families exert considerable influence on end-of-life care,⁹⁻¹¹ and that their involvement represents an important conceptual dimension of what constitutes a good death.^{12,13}

While existing studies provide insight into families' experiences in providing end-of-life care, there are several important gaps in knowledge. First, studies to date have predominantly relied on family members of decedents^{8,14} or individuals identified as actively dying.^{2,4} Yet, death is difficult to predict, and individuals thought to be near

death disproportionately represent particular terminal conditions or end-of-life trajectories.¹⁵⁻¹⁷ Likewise, relying on the recall of family members of decedents is suboptimal because remembrances of the intensity or experience of providing care may evolve subsequent to the event.^{18,19} Lastly, that the provision of end-of-life care may generate its own rewards³ and that individuals approaching death value their ongoing contributions to others²⁰ are concepts that have been recognized but are largely absent from empirical research to date.

This study addresses these gaps by drawing from a nationally representative survey that collected information from both chronically disabled community-dwelling older adults, and, for those who were receiving help from family or friends, their primary caregivers. Study participants were followed up over time to ascertain survival; in this study we examine the help study par-

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ticipants were receiving in their last year of life. Among individuals receiving help from family or friends, we investigate the nature and intensity of help provided by primary informal caregivers, use of community-based supportive services, and caregivers' perceptions of their role, including both related burdens and rewards.

METHODS

STUDY POPULATION

Data for this study were obtained from the 1999 National Long-Term Care Survey (NLTC) and the NLTC Informal Caregiver Survey (NICS). The NLTC is a nationally representative survey of Americans aged 65 years and older that was specifically designed to study the prevalence of chronic disability.^{21,22} Medicare enrollment files constituted the sampling frame; screening interviews were conducted to determine eligibility for a detailed interview. In-person community interviews were conducted with participants, or with proxy respondents when participants were unavailable or unable to respond. The response rate exceeded 97% for the 1999 NLTC community interview.²³ The NICS was conducted with the primary caregiver (relative or unpaid nonrelative) who provided the most hours of help to the NLTC participant with activities of daily living or instrumental activities of daily living in the week prior to the community interview. The design of the NICS has been described in detail elsewhere.²⁴

In this study we compare primary caregivers' experiences by care recipients' survival status, although our main objective was to elucidate the experiences of family caregivers providing end-of-life care. The NLTC and NICS were administered to participants and their primary informal caregivers during the fall of 1999 (the NLTC preceded the NICS since caregivers were identified in the NLTC). The 1999 NLTC participants' subsequent 12-month survival was based on the date of the NLTC participant interview and dates of death recorded in the vital statistics file. A total of 3115 community-dwelling NLTC participants screened into the NLTC as chronically disabled, of whom 1622 were determined to have been receiving assistance from an informal caregiver. Of these, 251 persons died within 12 months of interview and 182 of their caregivers completed the NICS (72.5% response). Among the 1371 chronically disabled NLTC participants who were receiving assistance from an informal caregiver and who survived 12 months following their interview, a total of 967 primary caregivers completed the NICS (70.5% response).

ESTIMATION AND DATA ANALYSIS

Observations from the NLTC and NICS must be weighted to produce nationally representative estimates and to account for its complex sampling strategies. Detailed community weights released with the NLTC were used in this study to generate population estimates of chronically disabled community-dwelling older adults. In addition, as outlined elsewhere,²⁴ we constructed weights for primary caregivers to chronically disabled community-dwelling older adults so as to generalize to caregivers nationally.

Demographic, economic, and health characteristics of chronically disabled older adults and chronically disabled older adults receiving help from an informal caregiver were first examined and were stratified by their survival throughout the 12 months following the date of their NLTC detailed community interview. We compared primary caregivers' sociodemographic characteristics, types of assistance provided, perceptions of their help-

ing role, and use of community and supportive services, stratified by recipients' survival status. All analyses were calculated using SAS version 9.1 software (SAS Institute Inc, Cary, NC) using the Taylor expansion method to account for the complex sampling strategy of the NLTC in estimating sampling errors. Estimates that cannot be considered reliable (relative standard errors exceeding 30%) are noted in the tables.

MEASUREMENTS

Key measures for care recipients included demographic characteristics (age, gender, race/ethnicity, and marital status [whether they were widowed]), living arrangement, socioeconomic factors (education, health insurance), and health status (self-rated health and functional disability). Personal assistance referred to active or standby help with activities of daily living (eating, bathing, dressing, toileting, transferring, and indoor mobility), and help with instrumental activities of daily living tasks (grocery shopping, transportation, laundry, light housework, managing money, meal preparation, using the telephone, medication management, and outdoor mobility) because of a health problem or disability.

For primary informal caregivers we examined age, gender, self-rated health, relationship to recipient (spouse, child, or other), and whether they lived with the care recipient. Information regarding caregiver commitment included duration of time providing help, frequency of help, hours of assistance provided in the previous week, and types of task assistance provided. Primary caregivers' perceptions included challenges, burdens, and rewards experienced in their role, as well as the reciprocal exchanges by the person to whom they provided assistance. Lastly, we examined use of community-based supportive services.

RESULTS

CHARACTERISTICS OF DESCENDENTS

Of an estimated 5.6 million chronically disabled older adults who were living in the community during 1999, 631 000 (11.2%) died within 12 months (**Table 1**). Relative to community-dwelling chronically disabled older adults who survived, individuals in the last year of life were significantly older and more likely to be male, to live with others, to report fair or poor health, and to carry a higher burden of functional disability.

A total of 72.3% of chronically disabled older adults in the last year of life were receiving help from family or friends compared with 48.6% of chronically disabled older adults who survived the following year. Relative to chronically disabled older adults who received informal help and who survived the following year, recipients of informal care in the last year of life were significantly more likely to be male, to report fair or poor self-rated health, and to carry a greater burden of functional disability.

HELP FROM FAMILY AND FRIENDS

Primary informal caregivers to individuals in the last year of life were spouses (41.5%), children (39.0%), and others (19.5%) (**Table 2**). End-of-life caregivers were, on average, 64 years of age, tended to be female (75.1%), and were mainly in excellent or good health (66.3%). The duration of time over which they had provided assistance varied from less than 1 year (26.5%) to over 4 years

Table 1. Chronically Disabled Community-Dwelling Older Adults and Receipt of Help From an Informal Caregiver by Survival Status Within 12 Months of Interview*

Variable	Overall		Chronically Disabled With Help	
	Chronically Disabled†		From Informal Caregiver‡	
	Survived	Died	Survived	Died
Weighted sample (%)	4 990 000 (88.8)	631 000 (11.2)	2 423 000 (84.2)	456 000 (15.8)
Proportion of chronically disabled			48.6	72.3
Age, y				
65-74	30.7	21.3§	29.6	23.2
75-84	43.2	40.9	41.5	40.6
>85	26.1	37.8	28.9	36.2
Female gender	70.1	53.1§	68.9	51.4§
White	86.4	90.1	85.8	89.0
<12 y Formal education	49.1	50.2	56.0	53.1
Health insurance				
Medicare only	29.6	29.7	29.6	24.6
Medicare and Medicaid/other public	20.8	19.7	24.4	23.0
Medicare and private supplemental	49.6	50.6	46.0	52.4
Widowed	50.0	47.3	45.6	42.4
Living arrangement				
Alone	39.0	28.0	23.3	17.9
With spouse or child	52.4	60.4	66.6	67.1
Other arrangement	8.6	11.5	10.0	12.8
Fair or poor self-rated health¶	53.0	72.5§	60.7	77.9§
Disabled in				
IADLs only	56.8	30.8§	30.0	14.8§
1-2 ADLs	20.6	20.4	31.2	26.8
≥3 ADLs	22.6	48.9	38.8	58.4

Abbreviations: ADLs, activities of daily living (eating, bathing, toileting, transferring, and indoor mobility); IADLs, instrumental ADLs (grocery shopping, transportation, laundry, light housework, managing money, meal preparation, using the telephone, medication management, and outdoor mobility).

*Data are given as percentage unless otherwise indicated. 1999 National Long-Term Care Survey and Informal Caregivers Survey.

†Survival status based on date of death within 12 months of completing the 1999 National Long-Term Care Survey detailed community interview.

‡Primary informal caregiver designated as either family member or unpaid non-relative caregiver who provides the most help with ADLs or IADLs.

§ $P < .001$, χ^2 test.

|| $P < .01$, χ^2 test.

¶Proportion reporting excellent or good health omitted.

(31.5%). End-of-life caregivers helped a mean of 43 hours per week; 84.4% provided daily assistance. They helped with shopping and transportation (85.3%), household tasks (82.8%), personal care and nursing (64.8%), finances (52.3%), administration of medicine (50.9%), and indoor mobility (38.6%).

Who served as primary caregiver, the likelihood of living with their care recipient, and self-rated health status did not vary significantly by recipients' survival. However, relative to primary informal caregivers of individuals who survived, end-of-life caregivers were significantly more likely to be female, to have helped for a shorter period, and to be providing more intense and frequent assistance with tasks relating to personal care and nursing and medication administration.

PERCEPTIONS OF THE CAREGIVER ROLE

Primary caregivers to individuals in the last year of life reported providing assistance when they did not feel well (53.5%), that their sleep was interrupted due to providing help (44.8%), that care recipients could not be left alone (36.8%), and that special medical care was required that they could not provide (18.5%) (**Table 3**).

These challenges tended to be significantly more common among end-of-life caregivers. End-of-life caregivers also reported significantly greater emotional (28.9%) and physical (18.4%) strains (but not financial strains) relative to other primary caregivers.

Large proportions of end-of-life primary caregivers endorsed statements regarding the rewards and reciprocity afforded by their helping role; the proportions were comparable in magnitude to that of other caregivers. Approximately 70% of end-of-life caregivers agreed or strongly agreed with the statement that helping "makes me feel good about myself" and "enables me to appreciate life more," and 76.0% of caregivers reported that helping made them "feel useful and needed." A substantial proportion of primary caregivers acknowledged reciprocated exchanges with the person to whom they provided assistance, reporting that recipients helped "keep me company" (65.0%), helped financially (26.0%), and helped with household chores (20.8%).

USE OF SUPPORTIVE SERVICES

Use of community-based supports that were most commonly reported by end-of-life caregivers included assis-

Table 2. Primary Caregivers to Chronically Disabled Community-Dwelling Older Adults by Survival Status Over Subsequent 12 Months*

Primary Caregiver Characteristics	Recipients' Survival Status†	
	Survived	Died
Overall sample (weighted)	2 423 000	456 000
Relationship to participant		
Spouse	37.7	41.5
Child	41.8	39.0
Other	20.6	19.5
Mean age	62.5	63.6
Female gender	66.0	75.1‡
Fair or poor self-rated health§	28.4	33.7
Lives with care recipient	67.5	72.2
Duration of providing assistance, y		
<1	16.7	26.5
1-4	29.4	38.3
>4	48.7	31.5
Frequency of help, days per week		
<3	17.3	6.6¶
3-6	9.1	8.7
7	72.5	84.4
Mean weekly hours of assistance provided	28.9	42.9
Help from others		
None	53.4	49.4
Unpaid help with or without paid help	27.7	29.9
Paid help only	18.9	20.7
Type of assistance provided#		
Shopping and/or transportation	85.3	85.3
Household tasks	76.7	82.8
Personal care and nursing	45.6	64.8
Finances	48.8	52.3
Administration of medicine	40.1	50.9¶
Indoor mobility	34.4	38.6

*Data are given as percentage unless otherwise indicated. 1999 National Long-Term Care Survey and Informal Caregivers Survey.
 †Survival status based on date of death within 12 months of completing the 1999 National Long-Term Care Survey detailed community interview.
 ‡ $P < .05$, χ^2 test.
 §Proportion reporting excellent or good health omitted.
 ¶ $P < .001$, χ^2 test.
 || $P < .01$, χ^2 test.
 #Personal care and nursing includes eating, dressing, bathing, and toileting; mobility (transferring and getting around); administration of medicine includes giving shots, injections, medicine, pills, or changing bandages; household tasks (meal preparation, light housework, and laundry; shopping and/or transportation [shopping for groceries, errands, outside mobility, and transportation]).

tive devices (62.3%), personal or nursing care services (37.2%), and home modifications (28.3%)—supportive services that are directed toward the health and functioning of recipients (**Table 4**). Services for housework (13.6%), delivered meals (11.2%), or transportation (6.2%) were less commonly used. In terms of traditional caregiver-related support services, less than 5% of all primary caregivers reported having participated in caregiver support groups, used respite services, or enrolled their loved one in a program outside the home. Relative to other primary caregivers, end-of-life caregivers reported statistically significant greater use of assistive devices and home modifications but were approximately half as likely to report the use of transportation services ($P < .06$) or respite care ($P < .06$).

Table 3. Primary Caregivers Perceptions of Providing Help to Chronically Disabled Community-Dwelling Older Adults by Survival Status Over Subsequent 12 Months*

Perceptions of Caregiving Role	Recipients' Survival Status†	
	Survived	Died
Overall sample (weighted)	2 423 000	456 000
Challenges		
Provide assistance when I don't feel well	36.9	53.5‡
My sleep is interrupted to provide help	20.9	44.8§
Recipient cannot be left home alone	20.5	36.8
Recipient needs special medical care I cannot provide	12.3	18.5
Burdens		
Emotional stress¶	14.6	28.9§
Physical strain¶	10.0	18.4‡
Financial hardship¶	9.7	14.0
Rewards		
Enables me to appreciate life more#	60.2	69.4
Helping makes me feel good about myself#	62.1	70.2
Makes me feel useful and needed	64.9	76.0
Reciprocal exchanges		
Keeps me company	59.5	65.0
Helps financially	28.9	26.0
Helps with household chores	35.6	20.8§

*Data are given as percentage unless otherwise indicated. 1999 National Long-Term Care Survey and Informal Caregivers Survey.
 †Survival status based on date of death within 12 months of completing the 1999 National Long-Term Care Survey detailed community interview.
 ‡ $P < .05$, χ^2 test.
 § $P < .001$, χ^2 test.
 ¶ $P < .01$, χ^2 test.
 #Rated 4 or 5 on a 5-point scale, where 1 indicates not at all, and 5, very much.
 #Rated on scale where 1 indicates disagree a lot; 4, agree; and 5, agree a lot.

COMMENT

Drawing from a nationally representative survey of chronically disabled community-dwelling older adults and their primary caregivers, this study confirms family and friends to be the chief providers of end-of-life assistance. Nearly three quarters of chronically disabled older adults in the last year of life received help from family and friends. Primary informal caregivers provided an average of 43 hours of help per week and 84.4% helped daily; supportive services were infrequently used. At the same time, a higher proportion of end-of-life primary informal caregivers endorsed personal rewards that accompanied their helping role than identified related emotional, physical, or financial strains.

The mean 43 hours of weekly assistance that was provided by end-of-life primary caregivers is substantially higher than what has been previously reported in national studies of family caregivers,^{24,25} and is comparable to the 46 hours of help reported by one end-of-life study conducted among caregivers of persons with dementia.⁵ Thus, chronically disabled older individuals within 1 year of death were receiving assistance equating to 1 full-time equivalent worker from their primary caregiver alone. This finding is pertinent to discussions on end-of-life care in that most studies regarding the costs of end-of-life care have limited their scope to those costs

Table 4. Supportive Services Used by Primary Caregivers and Chronically Disabled Older Adults by Survival Status Over Subsequent 12 Months*

Supportive Services Used	Recipients' Survival Status†	
	Survived	Died
Overall sample (weighted)	2 423 000	456 000
Obtained assistive device	47.6	62.3‡
Personal or nursing care service	33.8	37.2
Modified home	20.5	28.3§
Housework service	15.7	13.6
Home-delivered meals	12.5	11.2
Transportation service	12.3	6.2
Service to get some time away (respite)	8.1	3.7
Support groups for caregivers	4.9	3.2¶
Enrolled recipient in program outside home (eg, adult day care)	5.0	3.2¶

*Data are given as percentage unless otherwise indicated. 1999 National Long-Term Care Survey and Informal Caregivers Survey.

†Survival status based on date of death within 12 months of completing the 1999 National Long-Term Care Survey detailed community interview.

‡ $P < .01$, χ^2 test.

§ $P < .05$, χ^2 test.

||Estimates significantly different at $P < .06$.

¶Relative SE 30% or greater.

incurred by health insurance programs or to families out of pocket.²⁶⁻²⁸ While the economic value of assistance provided by family caregivers has been well documented in the literature,²⁹⁻³² it has not been adequately articulated as a dimension of end-of-life care.

Despite the intensity and challenges related to providing assistance, more than two thirds of end-of-life caregivers reported that they derived personal rewards from their helping role. Approximately 70% of caregivers reported that providing help “enables me to appreciate life more” and “makes me feel good about myself.” A notably greater proportion of end-of-life primary caregivers endorsed rewards associated with helping than identified emotional, physical, and financial burdens; a finding that, to our knowledge, has heretofore not been noted in the published literature. Importantly, whereas end-of-life caregivers were more likely to identify challenges and burdens than other long-term caregivers, they were no less likely to identify a sense of rewards. Quantifying these rewards is important because concerns about being burdensome are thought to loom large among individuals at the end of life,^{12,13} and are thought to be a factor in patients' end-of-life treatment decisions.^{4,33}

Seriously ill patients have expressed the importance of ongoing daily interactions with family and friends, and the ability to help others as components of a good death.^{13,20} Data from this study indicate that primary caregivers were readily able to identify reciprocated emotional, instrumental, and financial exchanges afforded to them by the person to whom they provided assistance. We are unaware of other studies that have examined mutuality of exchanges within caregiving dyads at the end of life; the frequency of these interactions and stated importance to seriously ill or dying patients suggest this topic merits further inquiry.

Results from this study indicate that few supportive services are used by chronically disabled older adults and their primary informal caregivers, regardless of survival. This finding is consistent with other work showing limited use of paid services by individuals nearing death,² and the low take-up of support services among informal caregivers.³⁴ We cannot comment on the presence or nature of barriers to accessing supportive services, or the extent to which these services were perceived as desirable or needed. That said, by quantifying nonmedical service use near the end of life, this study provides important insight on a topic that is not well understood³⁵ and that is highly relevant to policy makers interested in reconfiguring the health system to better address the needs of chronically disabled older adults and their families.

There are several important limitations of this study. The sample was restricted to older adults who were chronically disabled and we, therefore, cannot comment on help received by working-age adults or older adults without chronic disability. In addition, our categorization of help that individuals were receiving prior to death was assessed at a single point in time, while participants' health needs and personal care arrangements were not static. For example, individuals in the last year of life who were not receiving help from an informal caregiver carried a lower burden of functional disability, and it may well be that some portion of persons in this group had no need for personal care at the time they were interviewed. From this standpoint, the 72.3% of chronically disabled older adults who were found to have received help from family, friends, or both prior to their death may underestimate the reliance on family, because some portion of older adults who were categorized as being without help may have subsequently acquired a family caregiver. Likewise, families' experiences and perceptions in providing assistance may shift with impending death, yet we relied on a crude categorization that only accounted for 12-month survival.

The heterogeneity of the study sample inhibits our ability to describe caregivers' experiences by virtue of specific diseases, timing, or site of death, or to compare our findings with other evidence from the end-of-life literature. The particular constellation of disease or diseases being managed, decedents' end-of-life trajectory, and temporal proximity to death are all apt to influence families' experiences providing care. For example, understanding decedents' trajectories of dying could have helped inform our finding that end-of-life caregivers were less likely to be long-term caregivers.¹⁷ We would have ideally liked to have further examined families' experiences on several of these dimensions; however, the study sample was insufficient in size for this level of subanalysis. While we acknowledge the limitations of relying on a heterogeneous, population-based study sample, most of what is known about the circumstances of family care at the end of life has been derived from studies of individuals with a single disease,^{5,7,10} within a single setting,^{8,11} or with a clear dying trajectory.^{2,4,35} Although the sample of end-of-life caregivers is small, by drawing from a nationally representative survey this study provides valuable information about the end-of-life experience for a broader

population than has been typically represented in this literature.

Findings from this study have practical implications for physicians and other health care professionals. That nearly three quarters of chronically disabled older adults in the last year of life received help from an informal caregiver underscores the relevance of family to end-of-life patient care, and the potential benefit of productive collaborative relationships between physicians, patients, and families. Collectively, the literature on end-of-life caregivers suggests a role for physicians in monitoring the well-being of seriously ill or dying patients, as well as their caregivers; considering the health status and needs of both members of the caregiving dyad collectively, as a unit.^{7,36} However, the general perception of families, particularly family members of severely ill, hospitalized, or dying patients, is that communication with health care professionals is far from adequate.^{14,20,37-41} Although there has been some recognition that the health care community should better acknowledge the contributions and needs of patients' families and friends,⁴²⁻⁴⁴ much remains to be learned regarding how families should be integrated in medical care.⁴⁵ By doing so, health care professionals might better capitalize on families' ability to serve as a resource and ally in patient care, and potentially benefit both patients and their families.^{4,46,47}

This is, to our knowledge, the first study to draw from a nationally representative survey of primary informal caregivers to examine their experiences providing care to individuals in the last year of life. Information reported herein confirms the intensity and frequency of end-of-life care, and helps elucidate the pathway by which the provision of such assistance may generate adverse health consequences. Additional research leading to advances in the health care professionals' practice is much needed in this area, and will only grow in importance given evidence of declining in-hospital deaths, the demonstrated health effects of providing end-of-life assistance, and demographic trends that will make end-of-life care among chronically disabled older adults an increasingly common experience.

Accepted for Publication: September 27, 2006.

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Financial Disclosure: None reported.

Funding/Support: This study was supported in part by grant R03 AG025153-01 from the National Institute of Aging and an unrestricted grant from Pfizer Inc.

Role of the Sponsors: The sponsors of the study had no role in study design, data collection, data analysis, or writing of the manuscript.

Acknowledgment: We gratefully acknowledge the helpful comments of Albert Wu, MD, MPH.

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