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A national profile of end-of-life caregiving in the United States

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Abstract

Family and friends are the predominant providers of end-of-life care (EOL). Yet knowledge of the caregiving experience at the EOL has been constrained by a narrow focus on specific diseases or the “primary” caregiver and methodological limitations due to reliance on convenience samples, or recall biases associated with mortality follow-back study design. Using prospective, linked nationally representative datasets of Medicare beneficiaries and their caregivers, we found that in 2011 900,000 older adults at the EOL received support from 2.3 million paid and unpaid caregivers. Nearly 9 in 10 of these caregivers were family members or unpaid. EOL caregivers provided more extensive care and reported more care-related challenges (e.g., physical difficulty) than non-EOL caregivers. EOL challenges were especially prevalent among caregiving spouses. To meet the needs of older adults at the EOL, families and unpaid caregivers must be better recognized and integrated in care delivery and supportive services must be expanded and made more widely available.

BACKGROUND

Caregivers play a vital role in the care of older adults with disabilities and serious illness, including those at the end-of-life (EOL).^{1, 2} Caregivers may assume new and potentially challenging tasks as the EOL approaches, including symptom management, engaging in difficult decisions about transitioning to long-term care or hospice, serving as a surrogate in medical decisions, and hiring paid caregivers.^{3, 4} Furthermore, many older adults experience complex transitions between health care settings at the EOL,³ or may incur multiple hospitalizations, ICU admissions,⁵ or receive life-sustaining treatments.⁶ Service use may lead to high out-of-pocket spending for families⁷ as well as fragmented care, which further burden older adults and their caregivers.

Existing evidence suggests EOL caregiving demands are significant,^{8,9} and that certain tasks, such as decision-making, are extremely stressful.¹⁰ Watching a family member in pain or suffering is difficult.¹¹ Not surprisingly, EOL caregivers have been found to experience high levels of depression and anxiety.¹² Of particular concern is the consistent finding that EOL caregivers have high unmet needs themselves and that despite the high level of care they provide, use of supportive services (e.g., assistance with personal care or housework, use of respite care and support groups) is limited.^{13,14} Only 47% of bereaved family members report that their loved ones received “excellent” EOL care between 2011–2013, a decline from 57% in 2000.¹⁵

Our current knowledge of the scope and experience of EOL caregiving has been constrained by research limitations. Most studies that have reported on the experiences of EOL caregivers have relied on small convenience samples.^{4,16} Large-scale surveys on caregiving do not exclusively focus on EOL caregiving. Therefore, knowledge of EOL caregiving has generally been limited to specific disease groups or care settings,^{12,17,18} or to selected subpopulations identified as actively dying.^{19,20} Moreover, reliance on reports of caregiving experiences obtained after the assisted person’s death has made many studies subject to recall bias.^{21,22} Finally, most studies have been limited to assessing the experience of just one “primary” caregiver, failing to capture the full range of caregiving that occurs at the EOL.^{13,23}

Changes in care delivery and payment have expanded possibilities to better meet the needs of individuals with serious illness and support caregivers. There has been continued steady growth in the use of hospice,²⁴ including enrollment increases among individuals without cancer. Although not universally accessible, palliative care programs that focus on improving quality of life for patients and their families are increasingly available within large hospitals,²⁵ and are expanding to long-term care²⁶ and community-based settings.²⁷ A better understanding of the nature and intensity of EOL caregiving could prove useful to ongoing efforts to monitor and improve access and quality of hospice and palliative care.

Therefore, we draw on two nationally representative surveys that afford the ability to prospectively study the caregiving experience of older adults at the EOL. Specifically, we characterized the nature and intensity of help provided by family and other unpaid caregivers assisting with EOL care as well as their caregiving experiences, contrasting EOL caregivers with other caregivers providing ongoing care. Finally, because of known differences in caregiver outcomes based on caregiver relationship type²⁸ and the EOL trajectory,²⁹ we compared experiences for spousal versus non-spousal caregivers, and for caregivers to older adults with three highly prevalent conditions associated with late-life mortality.

METHODS

Sample

Data are drawn from the 2011 National Health and Aging Trends Study (NHATS) and its linked National Study of Caregiving (NSOC). NHATS,³⁰ a population-based survey of late-life disability trends and trajectories, drew a random sample of individuals ages 65 years and older living in the contiguous U.S. from the Medicare enrollment file on September 30, 2010

with oversampling of those over age 90 and non-Hispanic blacks. The enrollment file represents 96% of all older adults in the United States. In-person interviews were completed between May and November 2011 and yielded a sample of 8,245 persons, a 71% response rate; among these, 7609 were community-dwelling. Study participants were asked whether and how they performed daily activities in the month before the interview. Among older adults who received assistance for health and function, a detailed helper roster listed the relationship and specific activities for each person providing assistance.

NSOC³¹ is a nationally representative survey of family members and other unpaid caregivers who assist older persons with disabilities. NSOC participants were identified from the NHATS helper roster on the basis of being a family member or an unpaid helper who provided assistance with mobility, personal care, household activities, transportation, or medically oriented tasks. Up to 5 caregivers per older adult were interviewed. For older adults with more than 5 eligible caregivers, 5 caregivers were selected at random, and the remaining caregivers were considered ineligible.

The NHATS sample for our analysis consisted of 2423 community-dwelling older adults who received help with personal care, mobility or household activities from a family member or other unpaid helper. Older adults were classified as being at the EOL if they died within 12 months of completing the NHATS interview based on dates of death from the Medicare Master Beneficiary Summary file. Additionally, older adults who were identified as deceased within 12 months via the NHATS exit survey and who did not subsequently incur Medicare-reimbursed services were classified as being at the EOL (n=14). In total, 264 older adults were characterized as ‘end of life’ and 2159 older adults were characterized as ‘non-end of life’. At least 1 NSOC interview was completed with caregivers of 1369 eligible older adults resulting in a sample of 2007 family and unpaid caregivers who provided assistance (235 EOL and 1772 non-EOL)(Appendix).³²

Measures

Older adults’ demographic characteristics included age, gender, race, education, marital status, income, and living arrangements. Disease status was based on self-reports of whether a doctor had ever told study participants they had individual health conditions. Dementia status was based on report of clinical diagnosis, proxy responses to the Ascertain Dementia 8 (AD8), and cognitive testing.³³ Depression status was determined by a score ≥ 3 on the two-item Patient Health Questionnaire.³⁴ Receipt of help refers to older adults’ reports of assistance in the last month for personal care and mobility (bathing, dressing, eating, toileting, getting out of bed, getting around inside) and household activities (doing laundry, preparing meals, shopping, paying bills or handling medications) for health or function. Older adults reported whether anyone helped with these activities, whether help was paid or unpaid, source of payment if paid care, hours of care received, and each helper’s relationship to the respondent. Individuals who assisted older adults who died within 12 months were considered EOL caregivers.

Family and unpaid caregivers participating in NSOC reported on their socio-demographic and health characteristics, the nature and intensity of assistance they provided, and their experience of caregiving. Information regarding the nature and intensity of care provision

included duration of caregiving, intensity of help (hours of care in the previous week), and assistance with specific tasks in domains of disability-related activities, health system logistics, and health management tasks. Negative caregiving-related effects were also examined including depression and financial, emotional, and physical difficulty.

Analysis

We first present analyses in which the characteristics, nature, and experiences of helping networks and caregivers' experiences are examined by the survival status of the older adults they assisted. We describe national estimates and characteristics of all caregivers who assist older adults as well as the nature and intensity of care provided by family and unpaid caregivers. We next evaluate negative caregiving-related effects by older adults' survival for all family and unpaid caregivers, and for caregivers serving recipients with dementia, cancer, and heart disease. Finally, we examine differences in the characteristics of, nature of assistance provided by, and caregiving-related experiences of spousal versus non-spousal EOL caregivers. Observations from the NHATS and NSOC were weighted to produce nationally representative estimates.³² All analyses incorporated the use of survey design variables and analytic survey weights to account for differential nonresponse and the complex sampling design. Analyses of older adults use the NHATS weights.³⁵ When the unit of analysis was the caregiver, we used the NSOC weights³¹ which adjusts for differential probabilities of selection at both the NHATS sample person and caregiver levels. We compared differences between each group using t-tests and chi-square analyses. All analyses were completed using Stata version 13(College Station, Texas).

Limitations

Our care-recipient sample was limited to Medicare beneficiaries age 65 and older, so this study does not capture the experiences of EOL caregivers to younger individuals or to older adults not enrolled in the Medicare program. Although reports of help received and provided are subject to recall bias, the one-month recall period and prospective design limits this possibility. Furthermore, we only captured caregiving experience at the time of study interview (mean= 5 months before death), which may change as death approaches. Our study focused on individuals who lived in the community within the 12 months before death, including those living in assisted living facilities. We were not, however, able to include information on caregivers of individuals living in nursing homes before death, who were not surveyed in NSOC. Finally, we chose a previously defined¹³ cut-off of 12 months to define the EOL period. Depending on the individual's disease trajectory, it may not adequately capture the full range of EOL decision making and experiences.

RESULTS

The 264 (11%) community-dwelling older adults receiving help for health or function who died within one year of study enrollment represented an estimated 905,000 individuals nationwide. Individuals at the EOL were older, less likely to be female, in worse health, had more impaired function, and were more likely to have been hospitalized within the past year as compared with their counterparts who were not at the EOL (Exhibit 1). Consistent with

their greater severity of disability, older adults at the EOL were more likely to receive help with basic activities e.g., eating, bathing, and toileting than those who were not at the EOL.

Older adults at the EOL were more likely than those not at the EOL to be assisted by paid caregivers (20% vs. 14%). Just 9% of older adults at EOL received any caregiving support that was funded by government, state or private insurance, a percentage that was not significantly higher than those not at the EOL.

An estimated 2.3 million caregivers nationwide assisted older adults at the EOL (Exhibit 2). As compared with those who were not at the EOL, older adults at the EOL had greater numbers of caregivers (mean 2.5 vs. 2.2) and received almost twice as many hours of help per week (mean 61.3 vs. 35.3) from both paid and unpaid caregivers. While the vast majority of caregivers were unpaid family or friends regardless of survival, a greater percentage of total EOL caregivers were paid (11% vs. 8%) representing an estimated 260,000 paid individuals assisting older adults at the EOL. Almost half (125,000) of these paid caregivers were paid directly by older adults and/or their families.³²

An examination of help by disease type indicated that total number of caregivers, hours of help and receipt of any paid help was higher at the EOL than non-EOL for individuals with cancer, dementia and heart disease. Older adults at the EOL with heart disease were the most likely to receive any paid help regardless of payment source (33% for heart disease; 22% for cancer; 25% for dementia). While individuals at the EOL with cancer and heart disease were more than twice as likely as individuals with these diseases who were not at the EOL to receive help paid through government or other insurance, there was no significant difference by survival status among individuals with dementia (9% vs. 12%).³²

Among the estimated 2 million EOL caregivers who were unpaid family or friends, nearly half (46%) lived in the same household as the older adult (Exhibit 2). Although nearly one in three EOL caregivers(30%) were themselves age 65 and over, only 14% were spouses, a smaller percentage than caregivers of older adults who were not at the EOL(22%). More than one in ten EOL caregivers(14%) reported their own health to be poor or fair. Nearly one in four EOL caregivers(23%), an estimated 477,000 people nationwide, reported that they provided help without support of family or friends.

EOL caregivers provided help with a broader range of activities and with greater intensity than caregivers of older adults who survived (Exhibit 3). EOL caregivers spent significantly more time helping (22.9 vs. 16.1 hours per week) and were significantly more likely to provide help with mobility, personal care, transportation, making the home safer, obtaining mobility devices, and finding a paid helper than non-EOL caregivers. There were no significant differences in the proportion providing help with healthcare or health management activities based on older adults' survival status.

EOL caregivers were more likely to report caregiving-related physical difficulty (35% vs. 21%) and that they had no time for themselves (51% vs. 40%) compared to non-EOL caregivers (Exhibit 4). No significant differences were detected in depression, anxiety, and emotional or financial difficulty by survival status among all caregivers. Physical difficulty at EOL was especially pronounced among dementia caregivers (43%). Increased financial

difficulties at the EOL were only evident among cancer caregivers (30% vs. 19%) who also experienced the most substantial differences in emotional difficulties (41% non-EOL vs. 66% EOL). Dementia caregivers reported similarly high emotional difficulty regardless of older adults' survival status and no differences in negative aspects of caregiving were observed among caregivers of individuals with heart disease by older adults' survival status.

EOL caregivers who were spouses, an estimated 302,000, had been providing care for more years (mean=10.0) and for more hours per week (mean=44.1) than non-spousal EOL caregivers.³² They also were far less likely than other EOL caregivers to report that other family/friends provide help (38% vs. 84%). They were more likely to report caregiving to be physically difficult (66% vs. 30%) and were more than twice as likely to have depression compared to other EOL caregivers.

DISCUSSION

This nationally representative, prospective study finds that approximately 900,000 older adults in the last year of life were assisted by 2.3 million caregivers nationwide in 2011. We find that caregiving needs increase and caregiving networks expand as older adults approach the EOL. Families and unpaid caregivers provide the overwhelming majority of care. Although older adults receive more paid care towards the EOL, the vast majority do not receive paid help.

While EOL caregivers reported more negative aspects of caregiving than non-EOL caregivers, this was not consistently true across all domains. We did not observe differences in reports of financial difficulties, depression, anxiety, or that the caregiving role was more than EOL caregivers could handle. Our findings are consistent with previous literature indicating that the caregiving experience is generally stable and that coping style may be more important than disease severity in advanced illness.²³ The design of this study affords a more rigorous understanding of EOL caregiving in that the study is not constrained narrowly to a "primary" EOL caregiver, which may lead to over-reporting negative consequences.¹³ Moreover, by relying on a prospective design, this study is not subject to selection biases due to the enrollment of less-burdened families or recall biases due to reappraisal of the caregiving experience.³⁶

Our use of a nationally representative sample, as opposed to a disease-specific subgroup, allowed us to examine nuanced differences in the EOL caregiver experience for three common age-related conditions. Dementia caregivers reported a striking degree of physical difficulty regardless of older adults' survival status, which corresponds with extraordinarily high care needs of advanced dementia³⁷ and the physical toll associated with sleep interruptions, managing burdensome symptoms, and complete assistance with self-care activities.³⁸ The finding that financial difficulty was significantly higher among EOL cancer caregivers is notable in light of growing recognition and concern regarding the high costs of cancer care,³⁹ which may extend beyond patients to their families.

This work expands knowledge of the scope of EOL caregiving and its related challenges by examining all caregivers - both paid and unpaid - who are involved in the care of older

adults. While our work confirms the vital role of family and unpaid caregivers before and during the EOL period, we find that paid caregiving support is significantly higher at the EOL. However, just half of the paid support received at the EOL was funded by government, state or private insurance. Although individuals with cancer and heart disease received more government or insurance support for paid care at the EOL (vs. non-EOL), there was no significant increase in government-supported care for people at the EOL overall, including those with dementia. Together, these findings underscore the mismatch between older adults' care needs and current Medicare benefits. Specifically, Medicare's lack of long-term services and supports leaves many older adults and their families at risk for significant financial burden or impoverishment.⁷

Although they represented a small minority(14%) of EOL caregivers nationwide, spouses were disproportionately affected by the EOL caregiving trajectory. Spousal EOL caregivers experienced the most extensive care-related challenges including increased depression, and perhaps not surprisingly because of their older age, more exhaustion and physical difficulty. The negative experience of spousal EOL caregivers may in part be due to their increased likelihood of providing assistance alone, a finding previously reported.⁴⁰ Nearly 2/3, or an estimated 188,000 spousal caregivers nationwide, reported that they do not receive support from family or friends.

The lack of consistent differences in caregiving-related challenges by older adults' survival status speaks to the heterogeneity of family caregiving, and the necessity of understanding individual circumstances targeting effective interventions. This will require caregiver assessment,⁴¹ a systematic process of gathering information about a caregiving situation in order to tailor services, including direct assistance or respite care, and provide needed training and information. Furthermore, advancing policies that expand family leave and flexible workplaces are key strategies that will better enable caregivers to compensate for work-related impacts associated with caregiving demands.^{1,3}

The extensive health service interactions that were managed by all caregivers (EOL and non-EOL) reinforces recent recommendations by the National Academies of Sciences, Engineering, and Medicine for greater attention to identification and support of caregivers in care delivery,¹ and suggests the benefit of doing so earlier in the illness trajectory. Current policies which prioritize the privacy and security of individual patients' personal health information may impose barriers on families' ability to access information that is appropriate and beneficial when they are involved in overseeing, managing, or coordinating care for older adults without the capacity to do so themselves.⁴² Although engaging family members through health information technology holds promise as a strategy to respect patients' preferences for involving family and facilitating communication, awareness and uptake of such strategies remain low.⁴³

Palliative care provides an added layer of support for patients and families in the setting of serious illness, and is available at any point in one's illness. Hospice care, in contrast, is limited to the last months of life only and may arrive too late to fully benefit caregivers who have already experienced tremendous caring-related strain. Continued expansion of access to high quality hospice and palliative care programs, which have demonstrated effective

support for patients and their caregivers,⁴⁴ will be a critical tool to support EOL caregivers. The Medicare Care Choices Model demonstration project⁴⁵ is testing the effects of extending hospice support to individuals who may be ineligible or unwilling to use traditional hospice services. If successful, this strategy could facilitate delivery of supportive services to family caregivers earlier in the disease trajectory. Newly available billing codes that enable Medicare payment for voluntary advance care planning conversations, as well as transitional care and chronic care management services, including non-face-to-face conversations with family members¹ may also promote more proactive and meaningful support of families throughout the serious illness process.

CONCLUSIONS

Results from this study confirm the significant and enduring involvement of caregivers in meeting the needs of older adults at the EOL. Supporting the growing population of family and other unpaid caregivers is an urgent public health issue. Our findings indicate the need for adequate support is especially pressing when older patients and the loved ones who assist them are at their most vulnerable, at the EOL.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Exhibit 1

Characteristics of community-dwelling older adults who receive assistance by 12 month survival status, 2011

	Non End of life	End of life
Sample population	2159	264
National estimate	8,247,000	905,000
Sociodemographic factors	%	%
Age, mean	79.0	82.1 ***
Female	69.2	59.8 **
White	74.3	79.0
>= High School Education	66.2	65.1
Married	44.3	41.3
Enrolled in Medicaid	22.1	23.7
Lives Alone	32.1	32.3
Lives in assisted living	16.5	17.6 ***
Health status		
Fair or Poor Self-Rated Health	47.2	67.1 ***
Count medical conditions, mean	3.9	4.5 ***
Depression	28.2	40.2 ***
Probable dementia	27.0	47.0 ***
Cancer	27.2	33.5 *
Heart Disease	24.4	36.9 ***
Function		
Disability: 0 ADLs	49.0	26.4 ***
Disability: 1–2 ADLs	33.1	34.1
Disability: >= 3 ADLs	17.8	39.5 ***
Fall Last Month	18.9	29.4 ***
Hospital stay in the last 12 months	36.4	53.6 ***
Type of help received by older adults:		
Eating	12.1	23.7 ***
Bathing	21.4	42.9 ***
Toileting	8.8	24.0 ***
Dressing	30.9	42.2
Walking Inside	21.2	42.4 ***
Getting out of Bed	14.4	35.2 ***
Older adult receives any help from:		
Paid helper	14.2	20.5 ***

	Non End of life	End of life
Self-pay	7.6	10.0
Government/insurance	6.4	8.9
Family or unpaid helper		
Spouse/partner	42.2	38.6 ***
Daughter	50.1	56.5 ***
Son	33.6	40.7
Other family	23.5	23.2
Other non-relatives	16.5	18.0 ***

SOURCE: Authors' analysis of National Health and Aging Trends Study Wave 1

NOTES: Analyses were weighted to produce nationally representative estimates. There were 2,423 people in the study who received assistance with self-care or household activities, representing 9.2 million older adults; and 264 in the study who died within one year, representing 905,000 older adults.

End of life = died within 12 months; Self-rated health dichotomized as fair or poor vs. good, very good or excellent; Count of medical conditions based on self-report of heart attack, heart disease (including angina, congestive heart failure), high blood pressure, arthritis, osteoporosis, diabetes, lung disease, stroke, dementia/Alzheimer's disease, cancer, depression, anxiety and broken or fractured hip; Depression defined as a score of 3 or higher on the 2-item (feeling down, depressed, or hopeless and having little interest or pleasure in doing things) Patient Health Questionnaire; Dementia status based on report of diagnosis and cognitive testing; ADL= Activities of Daily Living; Self pay includes older adult or family; government/insurance includes Medicare, Medicaid, state programs and private insurance; multiple sources of payment for paid help may be reported.

*
p<0.10,

**
p<0.05,

p<0.01

Exhibit 2

Total caregiving help and characteristics of family and other unpaid caregivers by older adults' 12 month survival status, 2011

	Older adult non-EOL	Older adult EOL
Total caregivers		
Sample population	5020	682
National estimate	18,175,000	2,277,000
% caregivers paid	8.3%	11.4%***
Total help received		
Number caregivers per older adult, mean	2.2	2.5**
Hours of help received per week, mean	35.3	61.3***
Family and other unpaid caregivers		
Sample population	1772	235
National estimate	16,037,000	2,093,000
Characteristics		
Average age, mean	57.39	55.99
Female	61.98	60.67
Relationship to older adult		
Spouse	21.83	14.41**
Daughter	32.22	38.17
Son	20.81	22.30
Other family member	15.68	17.07
Non-relative	9.46	8.05
<High School Education	13.88	11.80
Has Children <18	15.83	13.23
Enrolled in Medicaid	10.12	10.80
Works for pay	40.42	44.47
Lives in household	43.72	46.69
Fair or poor self-reported health	21.21	14.64*
No family/friends help	30.1	22.8**

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SOURCE: Authors' analysis of National Study of Caregiving Wave 1 and National Health and Aging Trends Study Wave 1

NOTES: Analyses were weighted to produce nationally representative estimates of older adults and their caregivers. Number of caregivers (paid and unpaid) based on report via NHATS care-recipient. There were 5,702 total caregivers, representing 20.5 million caregivers, of NSOC-eligible older persons. Family and other unpaid caregivers refer to NSOC caregivers. NSOC interviews were completed by 2007 family and other unpaid caregivers representing 18.1 million caregivers. 235 NSOC caregivers were end of life representing 2.1 million EOL caregivers. Caregiver characteristics are based on NSOC responses. End of life = died within 12 months.

* p<0.10,
** p<0.05,
*** p<0.01

Exhibit 3

Nature of care provided by family and other unpaid caregivers by older adults' 12 month survival status, 2011

	Non End of Life	End of Life
Sample population	1772	235
National estimate	16,037,000	2,093,000
Duration of care, years, mean	7.1	6.2
Hours of care per week, mean	16.1	22.9 **
Activities provide assistance with	%	%
Personal care	30.9	58.5 ***
Mobility	50.1	70.9 ***
Shopping	76.4	73.2
Housework	67.4	74.3
Transportation	64.9	55.8 **
Banking	58.4	53.1
Making home safer	39.8	49.6 **
Finding a paid helper	17.3	25.0 **
Obtain mobility devices	41.0	51.0 **
Health system logistics		
Add/Change Insurance	24.4	29.1
Make Appointments	59.2	65.5
Order Medicine	47.4	50.5
Health care activities		
Medication management	48.3	56.7 *
Care coordination	64.4	69.5
Health management		
Diet	27.1	27.8
Foot Care	26.5	29.6
Skin Care	22.4	27.4
Exercises	21.1	20.2
Dental Care	14.2	19.0 *
Manage Medical Tasks	9.9	14.7 *

SOURCE: Authors' analysis of National Study of Caregiving Wave 1

NOTES: Analyses were weighted to produce nationally representative estimates of family and other unpaid caregivers. NSOC interviews were completed by 2007 family and other unpaid caregivers representing 18.1 million caregivers. 235 NSOC caregivers were end of life representing 2.1 million EOL caregivers. Assistance with activities in past month; Personal care, mobility, shopping, housework, and transportation dichotomized from questions about frequency as some days/most days/every day vs. rarely/never; Care coordination was defined by direct interactions with health care professionals; Medication management was defined as keeping track of medications or giving shots or injections.

* p<0.10,

** p<0.05,

p<0.01

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Family and other unpaid caregiver-reported negative aspects of caregiving by survival status and disease of older adult, 2011

Exhibit 4

	Disease type									
	All		Dementia		Cancer		Heart Disease			
	non End of Life	End of Life	non End of Life	End of Life	non End of Life	End of Life	non End of Life	End of Life		
Sample population	1772	235	608	131	465	77	457	82		
National estimate (millions)	16.0	2.1	4.8	1.1	4.2	0.8	4.0	0.8		
	%	%	%	%	%	%	%	%		
Exhausted when you go to bed	41.6	49.8*	49.2	57.3	41.3	47.0	43.2	52.67		
More than you can handle	42.8	45.1	51.0	52.9	40.6	38.7	43.9	46.9		
No time for yourself	40.0	50.6**	51.9	58.9	39.4	52.6*	50.4	55.2		
No routine	29.3	36.5*	36.6	44.1	27.2	36.2	37.3	37.9		
Financially difficult	22.8	23.2	30.1	28.4	19.1	30.1*	27.2	19.9		
Emotionally difficult	43.2	50.7*	53.0	52.4	40.7	66.2***	46.3	42.4		
Physically difficult	21.3	34.9***	27.0	42.6***	19.7	31.9**	27.6	38.1		
Depression	12.8	16.6	17.0	19.0	11.7	NR	13.8	10.7		
Anxiety	13.5	12.5	17.8	15.7	14.2	NR	16.1	13.9		

SOURCE: Authors' analysis of National Study of Caregiving

NOTES: Analyses were weighted to produce nationally representative estimates of family and other unpaid caregivers. NSOC interviews were completed by 2,007 family and other unpaid caregivers representing 18.1 million caregivers. 235 NSOC caregivers were end of life representing 2.1 million EOL caregivers. 739 caregivers cared for individuals with probable dementia representing 5.9 million caregivers, 1.1 million which were end of life. 542 caregivers cared for individuals with self-reported cancer representing 5.0 million caregivers, 761,000 of which were end of life. 539 caregivers cared for individuals with self-reported heart disease representing 4.8 million caregivers, 796,000 of which were end of life. Disease categories are not mutually exclusive as older adults may have multiple diseases. Financial, emotional, physical difficulty dichotomized based on any report of difficult due to caregiving for older adult³⁵; Depression defined as a score of 3 or higher on the 2-item (feeling down, depressed, or hopeless and having little interest or pleasure in doing things) Patient Health Questionnaire; Anxiety defined as a score of 3 or greater on the two item ("felt nervous, anxious, or on edge" and "been unable to stop or control worrying") (range = 0–6); NR= not reportable due to cell size restrictions based on data use agreement.

* p<0.10,

** p<0.05,

*** p<0.01