Published in final edited form as:

J Am Geriatr Soc. 2011 October ; 59(10): 1983–1984. doi:10.1111/j.1532-5415.2011.03610_15.x.

END-OF-LIFE AND FORMAL AND INFORMAL CARE USE OF COMMUNITY-DWELLING OLDER ADULTS WITH DIFFERENT LEVELS OF PHYSICAL DISABILITY

YongJoo Rhee, DrPh,

Mental Health Services and Policy Program, Department of Psychiatry and Behavioral Sciences;
Buehler Center on Aging, Health and Society, Feinberg School of Medicine, Northwestern
University, Chicago, Illinois

Howard B. Degenholtz, PhD,

Health Policy and Management, Graduate School of Public Health, Center for Bioethics and
Health Law, University of Pittsburgh, Pittsburgh, Pennsylvania

Denys T. Lau, PhD, and

Department of Pharmacy Administration, College of Pharmacy

Naoko Muramatsu, PhD

Community Health Sciences, Graduate School of Public, Health, University of Illinois at Chicago,
Chicago, Illinois

To the Editor

Providing end-of-life (EOL) care places an intense burden on family and other (unpaid) caregivers. Caregiving burden increases as the level of physical disability of the care recipient increases,¹ and the intensity of burden can increase dramatically before death.^{2–4} Approximately 20% of families in the United States provide care for older relatives at home and manage the burden of EOL care.⁵ Informal caregivers often make critical medical decisions and provide other assistance beyond hands-on care and social support.⁶ The emotional support that people who are dying is well recognized^{7,8} but difficult to measure.

Ability to perform activities of daily living (ADLs) is an important predictor of formal and informal care burden in older adults,¹ but it is unclear whether the relationship between ADLs and burden of care exists near the end of life. Little is known about different patterns of EOL care that family caregivers provide to older persons who die at home and survivors.

The current study used data for community-dwelling persons aged 65 and older from the Health and Retirement Study (HRS) (2002 EXIT, 827 decedents, 10,238 survivors) to investigate associations between the end of life and use of formal and informal care with different levels of physical disability. The study sample excluded persons who moved into a nursing home or other residential facility during the survey period ($n = 1,572$). The month before death was defined as the end of life. The amount of caregiving was numbers of hours per week.

Author Contributions: Rhee: Concept, design, data acquisition, analysis, interpretation of data, and preparation of manuscript. Degenholtz: Analysis, interpretation of data, and preparation of manuscript. Lau and Muramatsu: Interpretation of data and preparation of manuscript.

Conflict of Interest: Dr. Denys Lau was supported by Award K01AG027295 (PI: Denys T. Lau) from the National Institute on Aging.

Physical disability was measured using two variables representing the total number of difficulties with ADLs and instrumental ADLs (IADLs). Participants were into stratified four groups according to the number of ADLs and IADLs that they had difficulty with (no physical difficulty: 0 ADLs, 0 IADLs; low difficulty: 0 ADLs, >0 IADLs; midlevel difficulty: 1–3 ADLs, >0 IADLs; and high difficulty: 4–6 ADLs and >0 IADLs).

Decedents were significantly older (76.7 vs 74.5), were limited in more ADLs (1.9 vs 0.2) and IADLs (1.9 vs 0.4), and had a higher rate of severe cognitive impairment (18.5% vs 1.9%) than survivors. Decedents were more likely to have used informal (34.5% vs 9.8%) and formal (11.0% vs 1.7%) care and had significantly more health problems than survivors. Only approximately one-third of decedents lived with a spouse in the same household, compared with approximately half of survivors. Only 34.4% of decedents received informal care from a spouse, compared with 44.5% of survivors.

Table 1 presents the amount of formal and informal care use. *T*-tests were used to test average hours of formal and informal care for decedents and survivors. The average hours of informal care per week for those who did not have difficulties with ADLs and IADLs were significantly higher for decedents than survivors (14.6 vs 5.1, $P = .03$). The average hours of informal care for respondents with no difficulties in ADLs but any difficulties in IADLs were significantly higher for decedents than survivors (27.4 vs 13.7, $P = .009$). The group with midlevel difficulty (<3 ADLs, >0 IADLs) had significantly more average informal hours for decedents than survivors (57.5 vs 30.4, $P < .001$). There were no significant differences in the average hours of formal care between decedents and survivors in any of the four groups (no, low, midlevel, and high-level disability).

Adjusting for physical and cognitive disability and other factors, the probability of formal and informal care use was greater in decedents than in survivors. Decedents were significantly more likely to have more hours of formal and informal care than survivors. The association between the end of life and formal and informal care was significantly greater in older persons with fewer ADL disabilities than in those with more disabilities.

Providing EOL care carries an additional burden for caregivers, beyond what can be measured in terms of physical and cognitive disability. Adjusting for physical and cognitive disability and other factors, the probability of formal and informal care use was greater for decedents than survivors. For older persons who had any assistance, those who died were more likely to receive more hours of formal and informal care than survivors.

Family members and paid caregivers provide more assistance to older persons in the EOL period. Even after adjusting for physical and cognitive disability, end of life is associated with greater likelihood of receiving care and more hours of care.

The effect of the end of life on formal and informal care appears to be greater at lower levels of physical disability than higher levels, suggesting that providing care at home demands more than just personal assistance and household chores. Further research is needed into the different demands placed on families who provide EOL care beyond the well-recognized emotional strain of caring for a loved one during the dying process. In addition, policy-makers must recognize that there are limits to the amount of emotional support that formal paid caregivers can provide to persons dying at home, and that caregivers need education about risks of the negative effect of EOL care on psychological well-being during and after the EOL care process.

Acknowledgments

Sponsor's Role: The sponsors had no role in the design or execution of the research or preparation of this manuscript.

References

1. Allen S, Ciambone D. Community care for people with disability: Blurring boundaries between formal and informal caregivers. *Qual Health Res.* 2003; 13:207–226. [PubMed: 12643029]
2. Lo Sasso AT, Johnson RW. Does informal care from adult children reduce nursing home admissions for the elderly? *Inquiry.* 2002; 39:279–297. [PubMed: 12479539]
3. Van Houtven CH, Norton EC. Informal care and health care use of older adults. *J Health Econ.* 2004; 23:1159–1180. [PubMed: 15556241]
4. Hanley RJ, Wiener JM, Harris KM. Will paid home care erode informal support. *J Health Polit Policy Law.* 1991; 16:507–521. [PubMed: 1837037]
5. Weitzen S, Teno JM, Fennell M, et al. Factors associated with site of death: A national study of where people die. *Med Care.* 2003; 41:323–335. [PubMed: 12555059]
6. Hauser J, Kramer BJ. Family caregivers in palliative care. *Clin Geriatr Med.* 2004; 20:671–688. [PubMed: 15541619]
7. Schulz R, Hebert RS, Dew MA, et al. Patient suffering and caregiver compassion: New opportunities for research, practice, and policy. *Gerontologist.* 2007; 47:4–13. [PubMed: 17327535]
8. Steele R, Fitch MI. Supportive care needs of women with gynecologic cancer. *Cancer Nurs.* 2008; 31:284–291. [PubMed: 18600115]

Table 1
Comparisons of Informal and Formal Care Use According to Level of Physical Disability

Level of Physical Difficulty	Informal Care		Formal Care		P-Value	P-Value
	Decedents [*]	Survivors [†]	Decedents [*]	Survivors [†]		
–	% [‡]	–	% [‡]	–	–	–
None (0 ADLs, 0 IADLs)	14.6	5.1	23.3	8.2	.18	
Low (0 ADLs, >0 IADLs)	27.4	13.7	17.2	13.7	.59	
Mid (1–3 ADLs, >0 IADLs)	57.5	30.4	21.0	25.1	.62	
High (4–6 ADLs, >0 IADLs)	72.5	69.4	51.5	41.4	.14	

T-test was performed to test average hours of informal and formal care for decedents and survivors.

Average hours of formal and informal care were estimated only in participants with caregivers.

More than 16 hours of formal and informal care was imputed to a maximum of 16 hours per day.

^{*} All 2002 EXIT survey data for 827 older people represents 1,978,595 older people who died between 2000 and 2002.

[†] 10,238 respondents in HRS 2002 represent 33,439,700 older people in community.

[‡] All estimated percentages and means were weighted.

ADL = activity of daily living; IADL = instrumental activity of daily living.