

DR. KATHERINE ORNSTEIN (Orcid ID : 0000-0001-6270-4423)

DR. MELISSA GARRIDO (Orcid ID : 0000-0002-8986-3536)

Article type : Research Article

**Katherine Ornstein, PhD MPH (\*Corresponding author)**

Department of Geriatrics and Palliative Medicine

Institute for Translational Epidemiology

Icahn School of Medicine at Mount Sinai

Box 1070, One Gustave Levy Place

New York, NY 10029

[Katherine.ornstein@mssm.edu](mailto:Katherine.ornstein@mssm.edu)

Ph: 212-659-5555/ F: 212-849-2566

**Melissa M. Garrido, PhD**

James J Peters Veterans Affairs Medical Center

Department of Geriatrics and Palliative Medicine

Icahn School of Medicine at Mount Sinai

Box 1070, One Gustave Levy Place

New York, NY 10029

[melissa.garrido@mssm.edu](mailto:melissa.garrido@mssm.edu)

Ph: 718-584-9000

**Albert L. Siu, MD, MSPH**

This is the author manuscript accepted for publication and has undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the [Version of Record](#). Please cite this article as [doi: 10.1111/1475-6773.12841](https://doi.org/10.1111/1475-6773.12841)

This article is protected by copyright. All rights reserved

Department of Geriatrics and Palliative Medicine  
Icahn School of Medicine at Mount Sinai  
Box 1070, One Gustave Levy Place  
New York, NY 10029  
[albert.siu@mssm.edu](mailto:albert.siu@mssm.edu)  
Ph: 212-241-4290

**Evan Bollens-Lund, MA**

Department of Geriatrics and Palliative Medicine  
Icahn School of Medicine at Mount Sinai  
Box 1070, One Gustave Levy Place  
New York, NY 10029  
[evan.bollens-lund@mssm.edu](mailto:evan.bollens-lund@mssm.edu)  
Ph: 212-241-3160

**Kenneth M. Langa, MD PhD**

Department of Internal Medicine, Veterans Affairs Center for Clinical Management Research,  
Institute for Social Research, Institute for Healthcare Policy and Innovation  
University of Michigan, Ann Arbor, MI 48109  
[klanga@umich.edu](mailto:klanga@umich.edu)  
Ph: (734) 615-8341

**Amy S. Kelley, MD, MS**

Department of Geriatrics and Palliative Medicine  
Icahn School of Medicine at Mount Sinai  
Box 1070, One Gustave Levy Place  
New York, NY 10029

amy.kelley@mssm.edu

Ph: 212-241-1446

**MANUSCRIPT HSR-17-0315.R1**

**TITLE PAGE**

Impact of in-Hospital Death on Spending for Bereaved Spouses

Katherine A. Ornstein

Melissa M. Garrido

Albert L. Siu

Evan Bollens-Lund

Kenneth M. Langa

Amy S. Kelley

Corresponding author:

Katherine Ornstein, PhD MPH

Department of Geriatrics and Palliative Medicine

Icahn School of Medicine at Mount Sinai

Box 1070, One Gustave Levy Place

New York, NY 10029

Katherine.ornstein@mssm.edu

Ph: 212-659-5555/ F: 212-849-2566

**ABSTRACT**

**Objective**

This article is protected by copyright. All rights reserved

To examine how patients' location of death relates to healthcare utilization and spending for surviving spouses.

### **Data Sources/Study Setting**

Health and Retirement Study (HRS) 2000–2012 linked to the Dartmouth Atlas and Medicare claims data.

### **Study Design**

This was an observational study. We matched bereaved spouses whose spouses died in a hospital to those whose spouses died outside the hospital using propensity scores based on decedent and spouse demographic and clinical characteristics, care preferences and regional practice patterns.

### **Data Collection/Extraction Methods.**

We identified 1348 HRS decedents with surviving spouses. We linked HRS data from each dyad with Medicare claims and regional characteristics.

### **Principal Findings**

In multivariable models, bereaved spouses of decedents who died in the hospital had \$3,106 higher Medicare spending 12-months post-death ( $p=0.04$ ) compared to those whose spouses died outside a hospital. Those surviving spouses were also significantly more likely to have an ED visit ( $OR=1.5;p<0.01$ ) and hospital admission ( $OR=1.4;p=0.02$ ) in the year after their spouse's in-hospital death. Increased Medicare spending for surviving spouses persisted through the 24-month period post-death ( $\$5310;p=0.02$ ).

### **Conclusions**

Bereaved spouses of decedents who died in the hospital had significantly greater Medicare spending and healthcare utilization themselves after their spouses' death.

## KEY WORDS

End of life  
Caregiving  
Bereavement  
Treatment intensity  
Palliative care  
Medicare

## BACKGROUND

Caregivers play a vital role in the care of older adults with disabilities and serious illness across all disease stages including the end-of-life (EOL) period (Medicine 2014; National Academies of Sciences 2016; Ornstein et al. 2017b). Yet family caregivers are also at increased risk of poor health. Decades of research suggests that while there may be benefits to providing care (Cohen, Colantonio, and Vernich 2002; Roff et al. 2004; Tarlow et al. 2004), caregivers are also vulnerable to increased depression (Pinquart and Sorensen 2003) and other health problems (Buyck et al. 2013; Ho et al. 2009), and reduced preventive health behaviors (Reeves, Bacon, and Fredman 2012; Son et al. 2007). As a consequence, caregiving is often associated with increased healthcare costs (Schulz and Cook 2011; Van Houtven, Wilson, and Clipp 2005), and may even lead to increased mortality (Schulz and Beach 1999).

The experience of caring for loved ones at the EOL in particular may impact the health and well-being of the caregiver. Intensive Care Unit (ICU) admissions, for example, are associated with post-traumatic stress for caregivers (Anderson et al. 2008; Davidson, Jones, and Bienvenu 2012; Schmidt and Azoulay 2012). Families report worse physical and mental health following deaths when intensive, life-sustaining treatments were performed at EOL (Ornstein et al. 2017a; Wright et al. 2008). On the other hand, low intensity, comfort-focused treatments such as hospice, may mitigate the negative impact of caregiving on families. Beneficial effects of

hospice use on caregivers include better bereavement adjustment (Godkin, Krant, and Doster 1983; Seale 1991), increased satisfaction (Kane et al. 1985; Seale 1991; Teno et al. 2005), and decreased depression (Bradley et al. 2004; Ornstein et al. 2015a; Wright et al. 2010; Wright et al. 2008). Similarly, improved outcomes for family members including adjustment to death post-bereavement (Abernethy et al. 2008) and better reported quality of death (Garrido and Prigerson 2014) are associated with use of palliative care services .

Whether the impact of the patient's EOL treatment experience extends to family members' own healthcare utilization is largely unknown. Most caregivers increase their own utilization once caregiving ends and they can better attend to their own health needs (Guldin et al. 2013; Prigerson, Maciejewski, and Rosenheck 2000; Stroebe, Schut, and Stroebe 2007). But to date, there is a lack of research on what factors impact utilization of healthcare by surviving caregivers (Stajduhar et al. 2010). This is a remarkable gap in knowledge given that: (1) our social networks play a significant role in our own health behaviors and events (Smith and Christakis 2008) and (2) the negative health effects associated with caregiving are associated with reduced preventive health behaviors (Reeves et al. 2012), which may ultimately increase healthcare utilization. Understanding how the healthcare experience impacts family members is critical to the development of effective interventions to mitigate negative effects of caregiving. Moreover, advancing current policy initiatives designed to simultaneously improve health outcomes and the cost effectiveness of the healthcare system requires a better understanding of what the downstream effects of healthcare and treatment intensity are on the family.

### **Conceptual framework**

Our conceptual framework for understanding the impact of the patient's EOL care experience on family members' own healthcare (Ornstein et al. 2015b) is based on an adapted version of the Aday-Anderson behavioral model of healthcare utilization (Aday and Andersen 1974) and

incorporates the stress process model of caregiving (Pearlin et al. 1990), the role of patients' suffering on families (Schulz et al. 2009; Schulz et al. 2007), and shared social networks (Christakis 2004). We posit that family healthcare utilization may be related to patient treatment intensity because of shared values and preferences about healthcare, financial burdens related directly or indirectly to the patient's care, and the personal experience of witnessing the patient's symptoms, suffering, and challenging incidents within the healthcare system.

The Aday-Anderson model proposes that predisposing, enabling, and need characteristics influence access to and use of healthcare. Predisposing factors are the "immutable" characteristics of the family member (e.g., demographics) as well as their caregiving role both at the end of life and in the long-term. Enabling factors include resources individuals have available to them (e.g., insurance, regional service availability). Need factors refer to the conditions that necessitate healthcare utilization. The stress process model conceptualizes caregiving as a chronic stressor that gives rise to strains in multiple domains and ultimately leads to increased risk for psychiatric distress and physical illness burden. Furthermore, exposure to patient suffering (operationalized as physical, psychological and existential/spiritual) is an independent source of distress for caregivers. We posit that the intensity of healthcare treatment received by a patient influences patient symptoms, suffering, and costs, which in turn impact enabling factors for the family caregiver such as financial and time burden and lack of belief in the efficacy of the health care system. Because of this burden, there is a decrease in preventive and self-care behaviors, which ultimately results in increased urgent care use and healthcare spending for bereaved family members. Finally, family healthcare utilization is impacted by patient healthcare utilization within the context of shared social networks (Christakis 2004). Individuals are linked based on their social relationship within a social network, which are known to impact health behaviors such as smoking, weight gain, and cancer screening (Christakis and Fowler 2007). Behaviors such as use of high intensity treatments at EOL may be impacted by shared experiences within these social networks.

Guided by our model, the goal of this study was to test whether the EOL care experience of a person impacts the downstream healthcare utilization for surviving spouses. We conceptualize treatment intensity at the end of life as a high degree of medical intervention, most often taking place in a hospital setting. Although hospitalizations are the most common marker of treatment intensity, there is no uniform marker or timeframe (Luta et al. 2015). We focused on in-hospital death as a broad and commonly used marker of high intensity EOL treatment relevant to all decedents, not just those with a specific illness or in a specific setting (i.e. not just limited to those with cancer or hospitalized), as compared to death in a non-hospital location.

## **METHODS**

### **Study population**

The Health and Retirement Study (HRS), a nationally representative, longitudinal survey of U.S. adults 51 years of age and older (Health and Retirement Study 2013), interviews participants every two years. If participants are married or partnered, their partners (heretofore referred to as “spouses”) are recruited into the study and surveyed. During each interview cycle, HRS identifies participants who have died since the last interview wave. In these cases, a post-death interview is conducted with someone who is knowledgeable about the deceased participant. HRS survey data are linked for eligible participants with individual Medicare claims. Study participants provided informed consent upon enrollment and again for linkage to Medicare claims. We identified 3226 respondents who died between 2000-2011 and were survived by a spouse. Because our main outcome was spouse post-death utilization, we limited our sample to 1548 decedents whose spouses had completed an HRS interview, were over age 65, and had fee-for-service (FFS) Medicare at the time of the decedent’s death. Finally, we excluded 173 dyads due to missing data required for propensity score matching.

### **Measures**

Outcome Measures: The primary outcome was the surviving spouse’s total Medicare expenditures during the 12 months after their spouse’s death. This measure includes all



Medicare payments for inpatient, outpatient, skilled nursing facility, hospice and home care, as well as durable medical equipment. Claims spanning the 365<sup>th</sup> day after death were prorated to include only the expenditures within the one year period. We adjusted expenditures for inflation (2012\$) based on the consumer price index, and for geographic differences in Medicare price levels using the Centers for Medicare and Medicaid Services (CMS) wage index. We also used Medicare claims to determine if surviving spouses had any inpatient admissions or emergency department (ED) visits.

Independent Variables: Based on previous work (Kelley et al. 2011), we used HRS post-death interview data to create a binary indicator of in-hospital death vs. death in any other location. Being in the hospital at the time of death is indicative of a higher level of treatment intensity in the time immediately preceding death and is therefore distinct from death in other settings (home, assisted living, nursing home, hospice facility, and other), which were considered 'non-hospital death'.

Other Measures: Based on our group's conceptual frameworks for understanding multilevel predictors of treatment intensity (Kelley et al. 2010) and the impact of patient treatment intensity on family members' own healthcare (Ornstein et al. 2015b), we identified factors that could be associated with *both* likelihood of in-hospital death and spousal post-death healthcare spending. To account for this potential confounding, we used propensity score matching (as described below) based upon the following spousal, decedent and regional level variables.

Spousal factors drawn from the spouse's last HRS core interview before the patient's death included age, sex, race/ethnicity, education, net-worth, self-reported health, functional status, and level of comorbidity. We also identified whether the spouse was the primary helper with the decedent's activities of daily living (ADLs) or instrumental activities of daily living (IADLs) at the EOL from the post-death interview.

Decedent factors were extracted from decedents' final HRS core interview. HRS core interview data included the following: insurance coverage, functional status (whether the participant had difficulty with one or more basic ADLs), residential status (nursing home or community-dwelling), and self-reported health. Probable dementia was determined via clinically-validated algorithm (Hurd et al. 2013). Self-report illness data were used to determine cancer diagnosis and level of comorbidity. If the core interview was completed within the month before death, data were drawn from the previous interview. Presence of advance directives and whether or not the family expected the death were extracted from the post-death interview.

Using the decedent's zip code, each dyad was linked via their hospital referral region (HRR) to the Dartmouth Atlas of Healthcare's End of Life Expenditure Index (EOL-EI), a measure of physician practice patterns, based upon Medicare beneficiaries' utilization in the last 6 months of life (Wennberg and Cooper 2013). We created an indicator for those living in the top quartile of EOL-EI by HRR.

Analysis: Propensity scores were calculated using logistic regression of in-hospital death. Prior to matching, we checked the balance of covariates across the groups who did and did not die in-hospital within strata of the propensity score. We then used caliper matching with replacement to match those who died in-hospital to one or many decedents who died outside of the hospital within 0.02 of the standard deviation of the logit of the propensity score (Stuart 2010). Balance was then verified by examining standardized differences in covariates across treatment groups and variance of covariates before and after matching. Standardized differences < 10% indicated adequate balance (Austin 2009; Garrido et al. 2014).

Using the propensity-score matched sample, we first estimated differences in 12 month Medicare expenditures and hospitalization and ED visits based on non-parametric equality of medians test and chi-square test of proportions. In our primary analysis we estimated a multivariable generalized linear (GLM) model of 12 month Medicare expenditures post-death. Due to the skewed distribution of the outcome, we used a gamma distribution with a log

link. Regression coefficients were exponentiated into rate ratio estimates and average marginal effects were calculated to produce average treatment effects on the treated. For our secondary outcomes, incidence of hospitalization and ED admission 12 months post-death, we estimated multivariable logistic regression models. In all models we controlled for all covariates included in the propensity score to adjust for any remaining imbalance between the groups after matching (Stuart 2010). We also included an indicator for year of death to account for secular trends.

We conducted a series of sensitivity analyses. First we repeated the analyses described above using 24 months post-death spending as the outcome. We also repeated analyses limiting our sample to those spouses who survived at least 12 months beyond the death of their spouse. In order to account for individual variation in baseline spending, we limited our sample to those spouses with continuous FFS Medicare 18 months before death. We used the one-year period from 6-18 months before death to determine 'baseline spending' levels to avoid any deviation from typical healthcare utilization patterns due to the spouse's illness and approaching death. We repeated our analyses with only those spouses in highest baseline spending quartile. Finally, we included quartile of pre-death spending in our match and reran primary and secondary outcomes. For each additional analysis, we re-estimated the propensity score and created new matched subsamples with balanced observed covariates.

## **RESULTS**

Surviving spouses were mean age 77.8 years and 72.6% had at least a high school education (Table 1). The majority of surviving spouses (89.0%) were independent in all ADLs prior to their spouse's death (mean =12.7 months). Decedents had a mean age of 80.5 years at death. 69.2% percent were men, 85.8% were non-Hispanic white, and 68.1% had at least a high school education. More than one-third (38.9%) of decedents died in the hospital. The remainder died at home (including assisted living facilities) (32.0%), in a nursing home (18.4%) or in hospice facilities (8.7%).

Prior to matching, there were significant differences among dyads where the decedent died in the hospital compared to those who died elsewhere. Surviving spouses of those who died in the hospital were less likely to be non-Hispanic white (80.1% vs. 88.3%) and less likely to have a high school degree (69.5% vs. 74.5%). The decedents who died in the hospital were less likely to have dementia (23.1% vs. 31.4%), cancer (22.2% vs. 33.5%), be ADL dependent (31.1% vs. 42.1%), live in nursing homes (4.2% vs. 12.0%), have advance directives (55.5% vs. 62.8%), or have an expected death (48.1% vs. 67.0%). Those who died in the hospital were more likely to live in high spending EOL HRRs (32.3% vs. 23.5%) (Table 1).

In our matched sample (99.2% of complete sample), observed confounders were balanced (<10% standardized difference) (Table 1) (Austin 2009). Spouses of those who had an in-hospital death had consistently higher spending up to 24 months after death (See Figure 1). In bivariate analyses, spouses of those who died in the hospital had \$4000 higher Medicare expenditures during the 12 months after death ( $p<0.01$ ) and were more likely to be hospitalized (28.7% vs. 22.5%;  $p=0.02$ ) and visit the ED in the year after their spouse died than those whose spouses died outside of the hospital (39.2% vs. 30.8%;  $p<0.01$ ). These significantly higher levels of expenditures and utilization persisted for the 24-month period after death of a spouse (Table 2).

In multivariable analysis, in-hospital death was independently associated with a \$3106 mean increase in spousal Medicare expenditures over the first year ( $p=0.04$ ) and a \$5310 mean increase in spending over 2 years ( $p=0.02$ ) (Table 3). Spouses of those who died in the hospital had a 43% increased odds of being hospitalized in the 12 months following the death of their spouse ( $p=0.02$ ). Similarly, spouses of those who died in the hospital had a 51% increased odds of visiting the ED in the 12 months following the death of their spouse ( $p<0.01$ ). These differences in spending remained up to 24 months after the death of their spouse (See Table 3).

In 90% of dyads, the surviving spouse lived at least 12 months after the death of their spouse.

When limiting our analyses to these dyads, our findings remained unchanged (See Supplementary Table 1). In-hospital death was associated with 26% increased mean Medicare expenditures ( $p=0.04$ ).

Spouses' annual median baseline healthcare spending ranged from \$330 (lowest quartile) to \$21,082 (highest quartile) (See Supplementary Table 2). In matched fully adjusted analyses limited to the highest quartile of baseline spenders, there was a \$15,223 marginal difference in spending after death among spouses of those who died in the hospital ( $p<0.01$ ) compared to those who experienced a non-hospital death. This group also had a statistically significant two-fold increase in hospital and ED utilization 12 months after the death of their spouse. Significantly higher expenditures and likelihood of utilization were evident 24 months post-death (Table 4). We were unable to achieve adequate balance across all matching variables for the lower 3 quartiles when we stratified our analysis by quartile of spousal pre-death spending. In matched analyses that include quartiles of pre-death spending in the propensity score model (Supplementary Table 3), in-hospital death remained significantly associated with both 12-month hospitalization and ED utilization, although for Medicare spending the effect size was reduced and lost significance.

## **DISCUSSION**

Using a nationally representative sample of older decedents we found that bereaved spouses of those who died in the hospital had higher levels of Medicare spending and utilization themselves after the death, compared to those whose spouses died outside of a hospital. Specifically, we found that bereaved spouses of decedents who died in the hospital had more than \$3000 increased spending in the 12 months after death and over \$5000 increased spending in the 24 months after death, compared to otherwise similar surviving spouses. In addition, those whose spouses died in the hospital were significantly more likely to have an ED visit and a hospital admission after their spouse's death. Among those individuals in the highest

baseline spending quartile, in-hospital death was significantly associated with an even greater difference: \$15,000 higher spending 12 months post-death.

To our knowledge, this study is one of the first to demonstrate that the experience of the death of one's spouse may have an important impact on subsequent health care utilization and spending. Our work adds to a growing body of literature which finds that high intensity treatment including hospitalizations at the EOL may have negative consequences for some patients and their families (Christakis and Allison 2006; Ornstein et al. 2017a; Teno et al. 2004; Wright et al. 2016; Wright et al. 2010). This is of critical importance given that despite surveys indicating a preference among those with serious illness to avoid an in-hospital death and its associated use of high-intensity life-sustaining treatments, in-hospital death remains common (Barnato et al. 2009; Gomes et al. 2012). The proportion of deaths in acute care hospitals in the U.S. was 24.6% in 2009 (Teno et al. 2013), and the estimates are higher for cancer-related deaths (Bekelman et al. 2016).

Furthermore, these analyses suggest that assessment of EOL costs may need to account for the downstream costs of healthcare for spouses. Despite a growing literature demonstrating the evidence to support inclusion of family 'health spillovers' in economic evaluation (Al-Janabi and Van Exel 2016; Al-Janabi et al. 2016; Bobinac et al. 2011; Brouwer et al. 2013; Fletcher and Marksteiner 2017), current healthcare cost estimates do not routinely consider potential downstream costs associated with the healthcare expenditures of family members who care for their seriously ill loved ones (Hurd et al. 2013). A more comprehensive (and less individualistic) perspective on healthcare and assessment of costs is justified as many caregivers are themselves older, in poor health, and also Medicare beneficiaries (National Academies of Sciences 2016). Future research should examine if the same patterns are found among couples insured by private health plans.

By linking the healthcare experiences of individuals to their spouses, our work highlights the importance of meeting the needs of family caregivers. Adequate caregiver support throughout

the course of serious illness and during the EOL period is essential for high quality patient care and for caregiver well-being, but it may also have important implications for spending patterns for surviving spouses. While access to hospice is a core strategy to improve support for family caregivers at the end of life, supportive services available for caregivers through hospice may arrive too late to benefit caregivers who have already experienced substantial caring-related difficulties. Early palliative care services including caregiving support should be available at any stage of disease severity that requires caregiving support, and the impact of these services on families' health and healthcare outcomes must be evaluated. More generally, our findings highlight the importance of recognizing the impact of serious illness on families, and working to ensure families are fully considered in efforts to improve the quality and experience of care. Some examples of efforts to support families include improving reimbursement mechanisms for advance care planning discussions, expanding family medical leave and other legislation to support working family caregivers, and greater research into interventions designed to support EOL caregivers.

Our findings should be interpreted with a number of potential limitations in mind. Although the mortality follow-back sampling method has been critiqued (Bach, Schrag, and Begg 2004), this approach is appropriate for our research question that pertains specifically to the experience of decedents and the associated outcomes for surviving spouses. Because we used Medicare claims data to measure costs, we were limited to spouses with FFS Medicare. On average, individuals incur their highest medical costs in the last few months of life, so we did not exclude spouses who died during the 12 month follow-up period, which would bias our findings toward the null. In sensitivity analyses, we limited our study to 12 month survivors and also those with uninterrupted FFS Medicare and found no significant variation in results. Additionally, our use of propensity score matching, although robust, cannot adjust for unmeasured factors and unobserved differences between the groups. Importantly, although we examined a range of patient, spouse and regional characteristics that may have accounted for variation in both location of death and spousal post-death spending, we did not have detailed information on individual patient and family treatment preferences. We were thus unable to determine if

treatment was concordant with preferences. We also could not assess issues of prognostic uncertainty, provider communication, options around care choices, or overall satisfaction with the care received. Although we focus on all spouses regardless of their caregiving role, because provision of care is itself endogenous to the health of caregivers, causal effects are difficult to determine in observational data (Coe and Van Houtven 2009; Do et al. 2015). Finally, our findings regarding changing spending patterns must be interpreted with caution in light of findings on persistence of health spending (Hirth et al. 2015). Although our spending-related results were no longer significant when we included pre-death spending quartile in our match, this could be due to a reduced sample size or to a differential relationship between location and post-death spending according to level of pre-death spending. Unfortunately, lack of balance across quartiles precluded the examination of effects of location of death on spending across all levels of pre-death spending.

While our work demonstrates an association between having an in-hospital death and higher spouse post-death Medicare expenditures, it raises a number of issues that require further study. First, while we focused on site of death as a marker of treatment intensity, other relevant measures exist including number of hospital admissions or days, number of physician visits, number of transitions in sites of care, and use of life-sustaining interventions (Luta et al. 2015). Further examination of specific procedures and experiences may shed light on the association described in our study and could provide an opportunity for improved care quality for both the patient and spouse. Our study lacked detailed clinical data, so we cannot assess many of the specific treatments provided or the quality of communication and shared decision making. Future work could directly assess caregiver experience at the time of in-hospital death including possible mediating factors such as exacerbation of symptoms and high out-of-pocket expenditures. Similarly, further examination of reasons for spouse hospitalization and ED visits may help to determine how these may be prevented. For example, are these exacerbations of pre-existing illnesses or are they due to mental health crises that may be prevented through early increased caregiver support? The vast majority of spouse hospitalizations captured in this study post death (80%) were categorized as non-elective. In post-hoc analyses we found that



in-hospital death was similarly associated with a statistically significant increase in non-elective hospitalizations (data not shown). Moreover, we did not examine other sources of healthcare spending including individual out-of-pocket expenditures. A better understanding of these costs and household financial burdens could also reveal opportunities to provide necessary support services.

### **Conclusions**

A patient's family is increasingly recognized as an integral component of the healthcare system and a growing number of informal caregivers provide the bulk of long-term care in the community at huge unpaid costs (Levine et al. 2010). Meeting the needs of caregivers throughout the course of their loved one's serious illness and during the EOL period is a critical component of high quality care for patients and promotes caregiver well-being. Our findings highlight an association between location of death and the surviving spouse's subsequent healthcare utilization, suggesting that there may be an opportunity to better support the needs of caregiving families while lowering downstream healthcare costs.

**Table 1: Characteristics of spousal dyads by location of death before and after propensity score matching**

	Before matching			After matching		
	In-hospital death %	Non- hospital death %	Standardized Difference	In-hospital death %	Non- hospital death %	Standardized Difference
Sample n	528	831		526	822	
<b>SPOUSE</b>						
Age at death, years	77.6	78.0	0.06	77.6	77.7	0.01
Female	69.3	69.1	-0.01	69.6	69.0	-0.01
Networth, lowest quartile	15.9	15.9	-0.00	16.0	15.7	-0.01
Race, White, Non-Hispanic	80.1	88.39	0.23	80.4	81.7	0.03
Education, High School Degree	69.5	74.5	0.11	69.6	71.5	0.04
SRH poor or fair	32.6	31.9	-0.01	32.7	32.5	-0.00
No comorbidities	14.6	16.9	0.06	14.6	14.5	-0.00

Mild comorbidities	74.1	73.0	-0.03	74.0	74.1	0.00
Moderate/Severe comorbidities	11.4	10.4	-0.03	11.4	11.5	0.00
Dependent in ADLs	12.1	10.1	-0.06	12.0	11.6	-0.01
Primary caregiver EOL	52.7	57.3	0.09	52.9	53.2	0.01
<b>DECEDENT</b>						
Age at death, years	80.8	78.0	0.12	80.0	80.1	0.01
SRH poor or fair**	58.1	63.9	0.12	58.2	56.1	-0.04
Dependent in ADLs	31.1	42.1	0.23	31.0	29.7	-0.03
Probable dementia	23.1	31.41	0.19	23.2	22.6	-0.01
Cancer diagnosis	22.2	33.5	0.25	22.2	21.0	-0.03
No comorbidities	7.6	5.8	0.06	7.6	7.9	0.01
Mild comorbidities	67.6	69.9	-0.03	67.7	68.9	0.03
Moderate/Severe comorbidities	24.8	24.3	-0.03	24.7	23.2	-0.04
Nursing Home Resident	4.2	12.0	0.29	4.2	4.1	-0.01
VA Insurance	5.3	7.8	0.10	5.3	5.5	0.01
Had advance directive	55.5	62.8	0.12	55.5	56.6	0.02
Death expected by family	48.1	67.0	0.15	48.3	47.2	-0.02
<b>REGION</b>						

Quartile EOL spending by HRR: Low	14.6	18.7	0.11	14.6	15.3	0.02
Quartile EOL spending by HRR: Mid-low	18.8	24.7	0.14	18.8	19.7	0.02
Quartile EOL spending by HRR: Mid-high	34.3	33.2	-0.02	34.4	33.9	-0.01
Quartile EOL spending by HRR: High	32.4	23.5	-0.20	32.1	31.1	-0.02

SRH = Self-reported health; EOL= end of life; ADL = activities of daily living; VA= Veteran's Administration; HRR= Hospital Referral Region; Mild comorbidities = 1-3; Moderate/severe=>=4

**TABLE 2: Medicare expenditures and utilization for bereaved spouses post-death by location of death (matched sample)**

Post-death follow-up period		n	Mean Medicare expenditures, 2012\$	Median expenditures, 2012\$	Hospitalizations %	ED visits %

<b>12 months</b>	<b>In-hospital death</b>	526	15,959.7	3387.1	28.7	39.2
	<b>Non-hospital death</b>	822	11,775.5	3099.6	22.5	30.8
	<b>p-value</b>			<0.01	0.02	<0.01
<b>24 months</b>	<b>In-hospital death</b>	485	29,500.3	9725.3	42.9	58.4
	<b>Non-hospital death</b>	753	22,307.3	8382.3	35.7	48.1
	<b>p-value</b>			<0.01	0.02	<0.01

NOTES: Medicare expenditures are wage index & inflation adjusted to 2012\$. Sample propensity score matched based on: spouse age at death, gender, networth, race, education, self-reported health, comorbidity level, caregiving status; decedent age, self-reported health, ADL dependence, dementia status, cancer diagnosis, level of comorbidity, residence, insurance status; presence of advance directive; family expectation of death; and EOL spending by hospital referral region. p-values based on chi square test of proportions, non-parametric test of medians. Non-hospital death includes the following locations: home, assisted living, nursing home, hospice facility, and other. ED= Emergency Department.

**TABLE 3: Association between in-hospital death and Medicare expenditures and utilization for bereaved spouses post-death**

		<b>Post-death follow-up period</b>	
		<b>12 months</b>	<b>24 months</b>

	<b>N</b>	1348	1238
<b>Medicare expenditures</b>	<b>Rate ratio</b>	1.2	1.22
	<b>95% CI</b>	1.01-1.52	1.03-1.46
	<b>Average marginal effect</b>	\$3,105.81	\$5309.64
	<b>Median marginal effect (IQR)</b>	\$2,046.67 (\$1,358.24-\$3,876.56)	\$4,049.83 (\$2,863.32-\$6,432.91)
	<b>p-value</b>	0.04	0.02
<b>Hospitalizations</b>	<b>OR</b>	1.43	1.42
	<b>95% CI</b>	1.07-1.90	1.09-1.85
	<b>p-value</b>	0.02	0.01
<b>ED visits</b>	<b>OR</b>	1.51	1.60
	<b>95% CI</b>	1.16-1.96	1.23-2.08
	<b>p-value</b>	<0.01	<0.01

NOTES: Medicare expenditures are wage index & inflation adjusted to 2012\$. Sample propensity score matched based on: spouse age at death, gender, networth, race, education, self-reported health, comorbidity level, caregiving status; decedent age, self-reported health, ADL dependence, dementia status, cancer diagnosis, level of comorbidity, residence, insurance status; presence of advance directive; family expectation of death; and EOL spending by hospital referral region and adjusted for year of death. p-values

based on GLM and logistic regression models. ED= Emergency Department; IQR= Interquartile Range

**TABLE 4: Association between in-hospital death and Medicare expenditures and utilization for bereaved spouses post-death by high baseline spenders only**

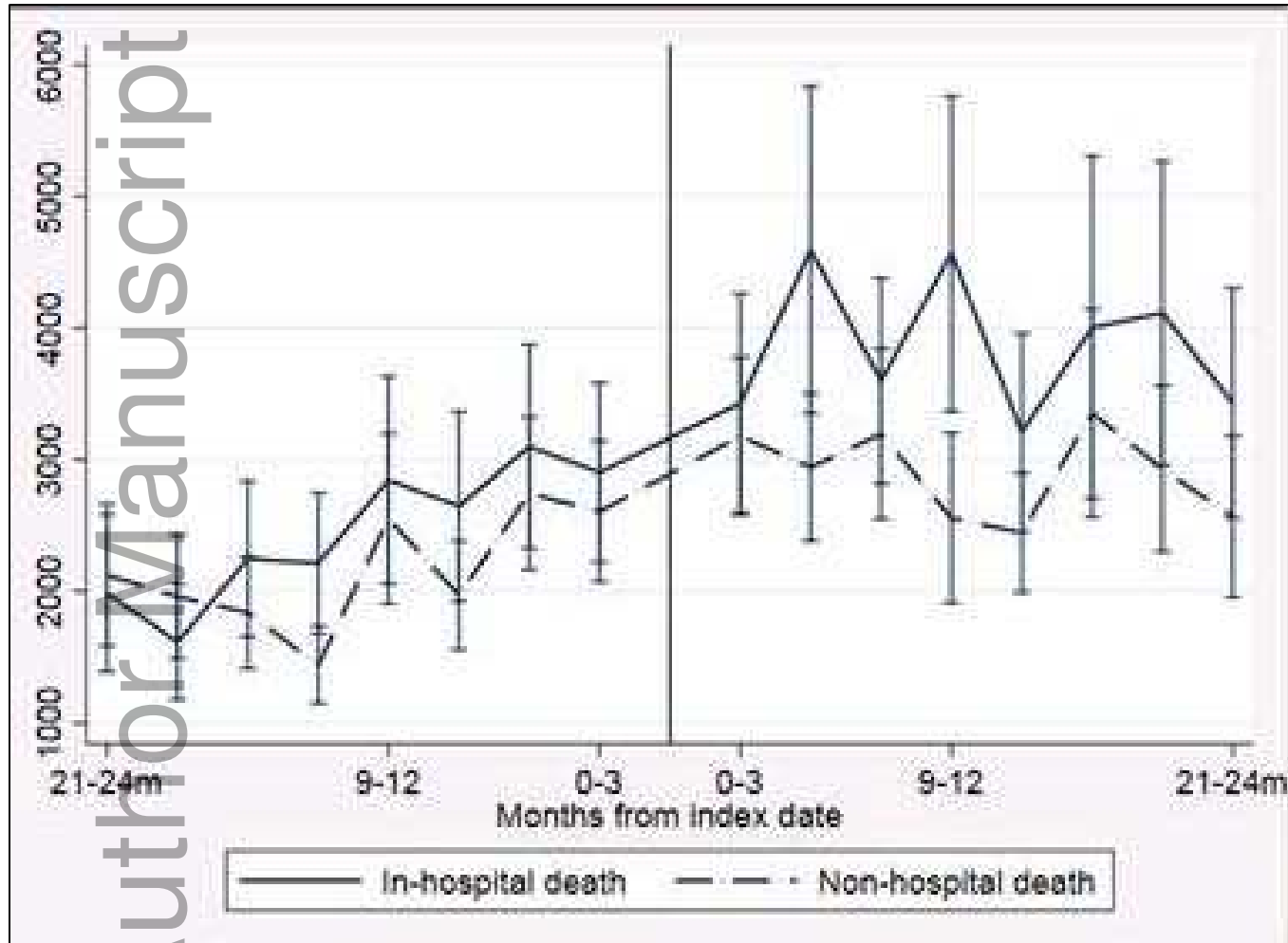
		Post-death follow-up period	
		12 months post-death	24 months post-death
	<b>N</b>	256	228
<b>Medicare expenditures</b>	<b>Rate ratio</b>	1.59	1.48
	<b>95% CI</b>	1.16-2.20	1.10-1.98
	<b>Average marginal effect</b>	15,223.47	20,761.83
	<b>Median marginal effect (IQR)</b>	\$12,417.08 (\$6,630.23-\$19,714.14)	\$16,144.51 (\$11,619.522-\$24,256.16)
	<b>p-value</b>	<0.01	<0.01
<b>Hospitalizations</b>	<b>OR</b>	2.34	1.84
	<b>95% CI</b>	1.23-4.44	0.94-3.57

	<b>p-value</b>	<0.01	0.07
<b>ED visits</b>	<b>OR</b>	2.27	1.96
	<b>95% CI</b>	1.22-4.24	0.99-3.90
	<b>p-value</b>	0.01	0.06

NOTES: Medicare expenditures are wage index & inflation adjusted to 2012\$. Sample propensity score matched based on: spouse age at death, gender, networth, race, education, self-reported health, comorbidity level, caregiving status; decedent age, self-reported health, ADL dependence, dementia status, cancer diagnosis, level of comorbidity, residence, insurance status; presence of advance directive; family expectation of death; and EOL spending by hospital referral region and adjusted for year of death. p-values based on GLM and logistic regression models. ED= Emergency Department; IQR= Interquartile Range.



Figure 1: Mean Medicare expenditures and 95% CI of bereaved spouses before and after death by location of death



NOTES: Medicare expenditures are wage index & inflation adjusted to 2012\$; Figure includes mean quarterly expenditures among those spouses with fee-for-service Medicare at the time of their spouse's death (n=1348; 2418.1 person years of follow-up after

death and 2399.8 person years of follow-up after death) adjusted based on propensity for in-hospital death; CI= Confidence Intervals

Author Manuscript

- Abernethy, A. P., D. C. Currow, B. S. Fazekas, M. A. Luszcz, J. L. Wheeler, and M. Kuchibhatla. 2008. "Specialized palliative care services are associated with improved short- and long-term caregiver outcomes." *Support Care Cancer* 16(6): 585-97.
- Aday, L. A. and R. Andersen. 1974. "A framework for the study of access to medical care." *Health Serv Res* 9(3): 208-20.
- Al-Janabi, H. and J. Van Exel. 2016. "Measuring Health Spillovers for Economic Evaluation: A Case Study in Meningitis." 25(12): 1529-44.
- Al-Janabi, H., J. van Exel, W. Brouwer, and J. Coast. 2016. "A Framework for Including Family Health Spillovers in Economic Evaluation." *Med Decis Making* 36(2): 176-86.
- Anderson, W. G., R. M. Arnold, D. C. Angus, and C. L. Bryce. 2008. "Posttraumatic stress and complicated grief in family members of patients in the intensive care unit." *J Gen Intern Med* 23(11): 1871-6.
- Austin, P. C. 2009. "Balance diagnostics for comparing the distribution of baseline covariates between treatment groups in propensity-score matched samples." *Stat Med* 28(25): 3083-107.
- Bach, P. B., D. Schrag, and C. B. Begg. 2004. "Resurrecting treatment histories of dead patients: a study design that should be laid to rest." *JAMA* 292(22): 2765-70.
- Barnato, A. E., D. L. Anthony, J. Skinner, P. M. Gallagher, and E. S. Fisher. 2009. "Racial and ethnic differences in preferences for end-of-life treatment." *J Gen Intern Med* 24(6): 695-701.
- Bekelman, J. E., S. D. Halpern, C. R. Blankart, J. P. Bynum, J. Cohen, R. Fowler, S. Kaasa, L. Kwietniewski, H. O. Melberg, B. Onwuteaka-Philipsen, M. Oosterveld-Vlug, A. Pring, J. Schreyogg, C. M. Ulrich, J. Verne, H. Wunsch, and E. J. Emanuel. 2016. "Comparison of Site of Death, Health Care Utilization, and Hospital Expenditures for Patients Dying With Cancer in 7 Developed Countries." *JAMA* 315(3): 272-83.
- Bobinac, A., N. J. van Exel, F. F. Rutten, and W. B. Brouwer. 2011. "Health effects in significant others: separating family and care-giving effects." *Med Decis Making* 31(2): 292-8.

- Bradley, E. H., H. Prigerson, M. D. Carlson, E. Cherlin, R. Johnson-Hurzeler, and S. V. Kasl. 2004. "Depression among surviving caregivers: does length of hospice enrollment matter?" *Am J Psychiatry* 161(12): 2257-62.
- Brouwer, W., C. Trotter, L. Glennie, L. Hannigan, J. Coast, E. Wittenberg, and L. A. Prosser. 2013. "Disutility of illness for caregivers and families: a systematic review of the literature." *Health Econ* 31(6): 489-500.
- Buyck, J. F., J. Ankri, A. Dugravot, S. Bonnaud, H. Nabi, M. Kivimaki, and A. Singh-Manoux. 2013. "Informal Caregiving and the Risk for Coronary Heart Disease: The Whitehall II Study." *J Gerontol A Biol Sci Med Sci*.
- Christakis, N. A. 2004. "Social networks and collateral health effects." *BMJ* 329(7459): 184-5.
- Christakis, N. A. and P. D. Allison. 2006. "Mortality after the hospitalization of a spouse." *N Engl J Med* 354(7): 719-30.
- Christakis, N. A. and J. H. Fowler. 2007. "The spread of obesity in a large social network over 32 years." *N Engl J Med* 357(4): 370-9.
- Coe, N. B. and C. H. Van Houtven. 2009. "Caring for mom and neglecting yourself? The health effects of caring for an elderly parent." *Health Econ* 18(9): 991-1010.
- Cohen, C. A., A. Colantonio, and L. Vernich. 2002. "Positive aspects of caregiving: rounding out the caregiver experience." *Int J Geriatr Psychiatry* 17(2): 148.
- Davidson, J. E., C. Jones, and O. J. Bienvenu. 2012. "Family response to critical illness: postintensive care syndrome-family." *Crit Care Med* 40(2): 618-24.
- Do, Y. K., E. C. Norton, S. C. Stearns, and C. H. Van Houtven. 2015. "Informal care and caregiver's health." *Health Econ* 24(2): 224-37.
- Fletcher, J. and R. Marksteiner. 2017. "Causal Spousal Health Spillover Effects and Implications for Program Evaluation." *American Economic Journal: Economic Policy* 9(4): 144-66.
- Garrido, M. M., A. S. Kelley, J. Paris, K. Roza, D. E. Meier, R. S. Morrison, and M. D. Aldridge. 2014. "Methods for Constructing and Assessing Propensity Scores." *Health Serv Res*.
- Garrido, M. M. and H. G. Prigerson. 2014. "The end-of-life experience: modifiable predictors of caregivers' bereavement adjustment." *Cancer* 120(6): 918-25.

- Godkin, M. A., M. J. Krant, and N. J. Doster. 1983. "The impact of hospice care on families." *Int J Psychiatry Med* 13(2): 153-65.
- Gomes, B., I. J. Higginson, N. Calanzani, J. Cohen, L. Deliens, B. A. Daveson, D. Bechinger-English, C. Bausewein, P. L. Ferreira, F. Toscani, A. Menaca, M. Gysels, L. Ceulemans, S. T. Simon, H. R. Pasman, G. Albers, S. Hall, F. E. Murtagh, D. F. Haugen, J. Downing, J. Koffman, F. Pettenati, S. Finetti, B. Antunes, and R. Harding. 2012. "Preferences for place of death if faced with advanced cancer: a population survey in England, Flanders, Germany, Italy, the Netherlands, Portugal and Spain." *Ann Oncol* 23(8): 2006-15.
- Guldin, M. B., A. B. Jensen, R. Zachariae, and P. Vedsted. 2013. "Healthcare utilization of bereaved relatives of patients who died from cancer. A national population-based study." *Psychooncology* 22(5): 1152-8.
- Health and Retirement Study. 2013. [accessed on 9/17/2013, 2013]. Available at: <http://hrsonline.isr.umich.edu/>.
- Hirth, R. A., T. B. Gibson, H. G. Levy, J. A. Smith, S. Calonico, and A. Das. 2015. "New evidence on the persistence of health spending." *Med Care Res Rev* 72(3): 277-97.
- Ho, S. C., A. Chan, J. Woo, P. Chong, and A. Sham. 2009. "Impact of caregiving on health and quality of life: a comparative population-based study of caregivers for elderly persons and noncaregivers." *J Gerontol A Biol Sci Med Sci* 64(8): 873-9.
- Hurd, M. D., P. Martorell, A. Delavande, K. J. Mullen, and K. M. Langa. 2013. "Monetary costs of dementia in the United States." *N Engl J Med* 368(14): 1326-34.
- Kane, R. L., S. J. Klein, L. Bernstein, R. Rothenberg, and J. Wales. 1985. "Hospice role in alleviating the emotional stress of terminal patients and their families." *Med Care* 23(3): 189-97.
- Kelley, A. S., S. L. Ettner, N. S. Wenger, and C. A. Sarkisian. 2011. "Determinants of death in the hospital among older adults." *J Am Geriatr Soc* 59(12): 2321-5.
- Kelley, A. S., R. S. Morrison, N. S. Wenger, S. L. Ettner, and C. A. Sarkisian. 2010. "Determinants of treatment intensity for patients with serious illness: a new conceptual framework." *J Palliat Med* 13(7): 807-13.
- Levine, C., D. Halper, A. Peist, and D. A. Gould. 2010. "Bridging troubled waters: family caregivers, transitions, and long-term care." *Health Aff (Millwood)* 29(1): 116-24.

Luta, X., M. Maessen, M. Egger, A. E. Stuck, D. Goodman, and K. M. Clough-Gorr. 2015. "Measuring intensity of end of life care: a systematic review." *PLoS One* 10(4): e0123764.

Medicine, I. o. 2014. *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. Washington, DC: The National Academies Press.

National Academies of Sciences, E., and Medicine. 2016. *Families Caring for an Aging America*. Washington, DC: The National Academies Press.

Ornstein, K. A., M. D. Aldridge, M. M. Garrido, R. Gorges, E. Bollens-Lund, A. L. Siu, K. M. Langa, and A. S. Kelley. 2017a. "The Use of Life-Sustaining Procedures in the Last Month of Life Is Associated With More Depressive Symptoms in Surviving Spouses." *J Pain Symptom Manage* 53(2): 178-87 e1.

Ornstein, K. A., M. D. Aldridge, M. M. Garrido, R. Gorges, D. E. Meier, and A. S. Kelley. 2015a. "Association Between Hospice Use and Depressive Symptoms in Surviving Spouses." *JAMA Intern Med* 175(7): 1138-46.

Ornstein, K. A., K. Boerner, A. L. Siu, and R. Schulz. 2015b. "Downstream Effects of End-of-Life Care for Older Adults with Serious Illness on Health Care Utilization of Family Caregivers." *J Palliat Med* 18(9): 736-7.

Ornstein, K. A., A. S. Kelley, E. Bollens-Lund, and J. L. Wolff. 2017b. "A National Profile Of End-Of-Life Caregiving In The United States." *Health Aff (Millwood)* 36(7): 1184-92.

Pearlin, L. I., J. T. Mullan, S. J. Semple, and M. M. Skaff. 1990. "Caregiving and the stress process: an overview of concepts and their measures." *Gerontologist* 30(5): 583-94.

Pinquart, M. and S. Sorensen. 2003. "Differences between caregivers and noncaregivers in psychological health and physical health: a meta-analysis." *Psychol.Aging* 18(2): 250-67.

Prigerson, H. G., P. K. Maciejewski, and R. A. Rosenheck. 2000. "Preliminary explorations of the harmful interactive effects of widowhood and marital harmony on health, health service use, and health care costs." *Gerontologist* 40(3): 349-57.

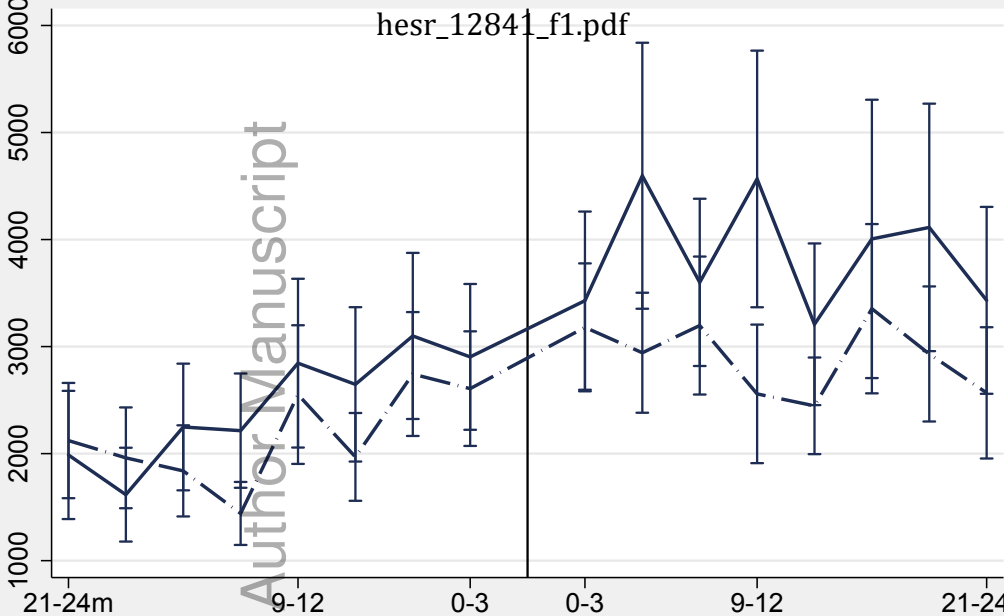
Reeves, K. W., K. Bacon, and L. Fredman. 2012. "Caregiving associated with selected cancer risk behaviors and screening utilization among women: cross-sectional results of the 2009 BRFSS." *BMC Public Health* 12: 685.

- Roff, L. L., L. D. Burgio, L. Gitlin, L. Nichols, W. Chaplin, and J. M. Hardin. 2004. "Positive aspects of Alzheimer's caregiving: the role of race." *J Gerontol B Psychol Sci Soc Sci* 59(4): P185-90.
- Schmidt, M. and E. Azoulay. 2012. "Having a loved one in the ICU: the forgotten family." *Curr Opin Crit Care* 18(5): 540-7.
- Schulz, R. and S. R. Beach. 1999. "Caregiving as a risk factor for mortality: the Caregiver Health Effects Study." *JAMA* 282(23): 2215-19.
- Schulz, R., S. R. Beach, R. S. Hebert, L. M. Martire, J. K. Monin, C. A. Tompkins, and S. M. Albert. 2009. "Spousal suffering and partner's depression and cardiovascular disease: the Cardiovascular Health Study." *Am J Geriatr Psychiatry* 17(3): 246-54.
- Schulz, R. and T. Cook. 2011. "National Alliance for Caregiving. Caregiving Costs: declining health in the Alzheimer's caregiver as dementia increases in the care recipient" [accessed on April 4, 2011]. Available at: [http://www.caregiving.org/pdf/research/Alzheimers\\_Caregiving\\_Costs\\_Study\\_FINAL.pdf](http://www.caregiving.org/pdf/research/Alzheimers_Caregiving_Costs_Study_FINAL.pdf).
- Schulz, R., R. S. Hebert, M. A. Dew, S. L. Brown, M. F. Scheier, S. R. Beach, S. J. Czaja, L. M. Martire, D. Coon, K. M. Langa, L. N. Gitlin, A. B. Stevens, and L. Nichols. 2007. "Patient suffering and caregiver compassion: new opportunities for research, practice, and policy." *Gerontologist* 47(1): 4-13.
- Seale, C. 1991. "A comparison of hospice and conventional care." *Soc Sci Med* 32(2): 147-52.
- Smith, K. P. and N. A. Christakis. 2008. "Social networks and health." *Annual Review of Sociology* 34: 405-29.
- Son, J., A. Erno, D. G. Shea, E. E. Femia, S. H. Zarit, and M. A. Stephens. 2007. "The caregiver stress process and health outcomes." *J Aging Health* 19(6): 871-87.
- Stajduhar, K., L. Funk, C. Toyne, G. Grande, S. Aoun, and C. Todd. 2010. "Part 1: Home-based family caregiving at the end of life: a comprehensive review of published quantitative research (1998-2008)." *Palliat Med* 24(6): 573-93.
- Stroebe, M., H. Schut, and W. Stroebe. 2007. "Health outcomes of bereavement." *Lancet* 370(9603): 1960-73.

- Stuart, E. A. 2010. "Matching methods for causal inference: A review and a look forward." *Statistical Science* 25(1): 1-21.
- Tarlow, B. J., S. R. Wisniewski, S. H. Belle, M. Rubert, M. G. Ory, and D. Gallagher-Thompson. 2004. "Positive Aspects of Caregiving: Contributions of the REACH Project to the Development of New Measures for Alzheimer's Caregiving." *Research on Aging* 26(4): 429-53.
- Teno, J. M., B. R. Clarridge, V. Casey, L. C. Welch, T. Wetle, R. Shield, and V. Mor. 2004. "Family perspectives on end-of-life care at the last place of care." *JAMA* 291(1): 88-93.
- Teno, J. M., P. L. Gozalo, J. P. Bynum, N. E. Leland, S. C. Miller, N. E. Morden, T. Scupp, D. C. Goodman, and V. Mor. 2013. "Change in end-of-life care for Medicare beneficiaries: site of death, place of care, and health care transitions in 2000, 2005, and 2009." *JAMA* 309(5): 470-7.
- Teno, J. M., V. Mor, N. Ward, J. Roy, B. Clarridge, J. E. Wennberg, and E. S. Fisher. 2005. "Bereaved family member perceptions of quality of end-of-life care in U.S. regions with high and low usage of intensive care unit care." *J Am Geriatr Soc* 53(11): 1905-11.
- Van Houtven, C. H., M. R. Wilson, and E. C. Clipp. 2005. "Informal Care Intensity and Caregiver Drug Utilization." *Review of Economics of the Household* 3(4): 415-33.
- Wennberg, J. E. and M. Cooper. 2013. "The Dartmouth Atlas of Health Care" [accessed on 9/17/2013, 2013]. Available at: <http://www.dartmouthatlas.org/>.
- Wright, A. A., N. L. Keating, J. Z. Ayanian, E. A. Chrischilles, K. L. Kahn, C. S. Ritchie, J. C. Weeks, C. C. Earle, and M. B. Landrum. 2016. "Family Perspectives on Aggressive Cancer Care Near the End of Life." *JAMA* 315(3): 284-92.
- Wright, A. A., N. L. Keating, T. A. Balboni, U. A. Matulonis, S. D. Block, and H. G. Prigerson. 2010. "Place of death: correlations with quality of life of patients with cancer and predictors of bereaved caregivers' mental health." *J Clin Oncol* 28(29): 4457-64.
- Wright, A. A., B. Zhang, A. Ray, J. W. Mack, E. Trice, T. Balboni, S. L. Mitchell, V. A. Jackson, S. D. Block, P. K. Maciejewski, and H. G. Prigerson. 2008. "Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment." *JAMA* 300(14): 1665-73.



Author Manuscript



This article is not certified by peer review. All rights reserved.

