



RESEARCH METHODS

Hospitalizations of Caregivers Increases Risk of Hospitalization for Patients Living with Dementia

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INTRODUCTION

Caregivers for people living with dementia (PLWD) make up a diverse group of individuals and can include family, friends, and paid direct care workers. Nearly 30% of caregivers in the USA report caring for a PLWD.¹ Those living in the same household, frequently the spouse of the PLWD, provide the bulk of care and are instrumental to a PLWD's quality of life.^{2–4} Research finds that spousal caregivers of a spouse with dementia in the last years of life are likely to be the sole caregiver.⁴ While providing care to a spouse can be rewarding,⁵ some spousal caregivers may feel caregiver burden and become self-neglectful (e.g., eating poorly, poor exercise habits, sleep deprivation),^{1, 6} which have the potential to lead to poor health outcomes among caregivers.^{1, 6, 7} Previous research also finds that caregiver burden is associated with higher risk for emergency department (ED) use and hospitalization among care recipients.^{8–10}

Serious, unexpected health events such as hospitalization of the caregiver can become a major disruption to the spousal caregiving relationship. However, little research has examined the effect of health events for the caregiver and the impact on the health of the PLWD. In addition, often the caregiver has not planned for such unexpected events where they may become ill.^{11, 12} Interventions that support a caregiver can reduce caregiver burden and delay or offset the need to place a PLWD in a care facility.^{13–15}

Here we use private insurance data to link both the care recipients' and caregivers' health records. Kaiser Permanente Colorado (KPCO) is part of the larger KP regional nonprofit health care provider and insurer, which offers managed Medicare through a KP Medicare Advantage plan. KPCO insurance coverage and membership data allowed us to create a cohort of spousal caregiver-PLWD dyads and identify time periods

when they lived together and shared the same KPCO insurance plan coverage. Development of this cohort allowed measurement of the potential impact of health outcomes of one spouse on the other. Other health plans would potentially be able to also adopt this approach and even conduct interventions with measurement of outcomes prospectively.

The goal of this work is to test a new methodology for identifying spousal caregiver-PLWD dyads in the electronic health record (EHR) and thus link outcomes between spousal caregivers and PLWD. To this end, hospitalization rates for caregivers and the PLWD and the timing of such events overall and in relation to each other are described. The hypothesis is that a PLWD will have an increased risk of hospitalization if their caregiver was hospitalized in the previous 180 days. In turn, the long-term goal is to provide a methodology to determine the effect of interventions that target the caregiver and measure outcomes in both the caregiver and the PLWD.

METHODS

Setting and Data Sources

This retrospective cohort study was conducted at KPCO, an integrated, not-for-profit health care delivery system that provides health care to approximately 540,000 persons in Colorado. We utilized data from the ambulatory EHR used to maintain patient records as well as Virtual Data Warehouse tables that collate demographic, enrollment, benefit policies, diagnoses, and health care utilization from both internal visits and external claims. This research was approved by the KPCO Institutional Review Board.

Identification of a Cohort of Spousal Caregiver-PLWD Dyads

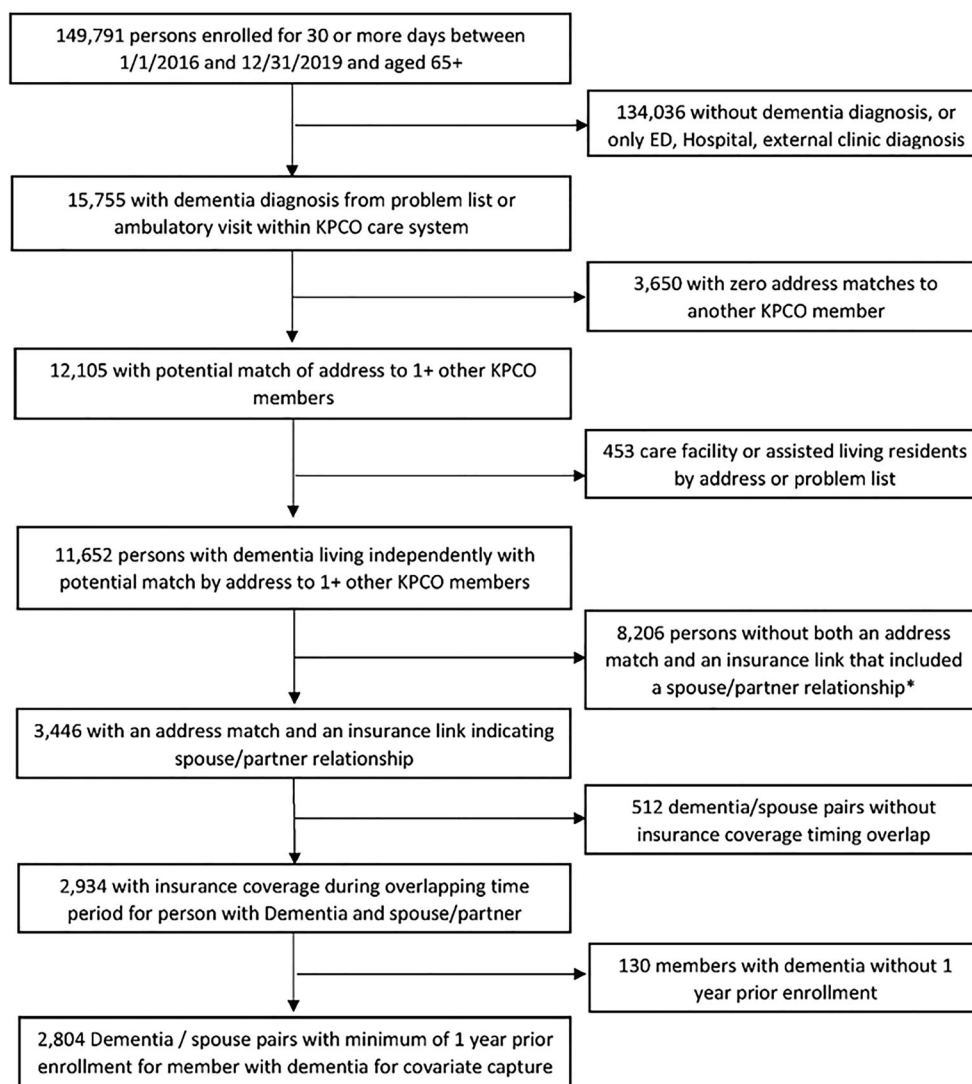
Initially, we identified 15,755 members aged 65+ with a dementia diagnosis between 1/1/2016 and 12/31/2019 (Fig. 1). Eligible start dates were the first date a person was aged 65 with a dementia diagnosis within this period. KPCO member diagnoses were identified from the EHR problem list or a diagnosis at a KPCO ambulatory visit. The EHR problem list is carefully monitored and frequently updated by primary care providers and is the best source for diagnostic accuracy at KPCO. To avoid

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*See Appendix for additional details.

Figure 1 Identification of spousal caregiver-PLWD dyads: A detailed flow diagram that outlines the steps taken to identify spousal caregivers and persons living with dementia from an electronic health record.

misdiagnosis, diagnoses uniquely from ED, hospitalizations, or external outpatient visits (outside KPCO) were not included.

With the goal of identifying the most likely potential spousal caregiver-PLWD dyad, we identified those who lived in the same private household and had KP insurance.¹ The spousal caregiver-PLWD dyads were identified by using both their street address and available links via KPCO insurance coverage databases. Insurance coverage identifies family members who are covered by the same insurance policy and specifies their relationship to the policyholder. For example, in our data, relationships included spouse, domestic partner, child, and other less common designations. Spouse and domestic partners were combined and studied further in these analyses while other family matches were grouped together and briefly described in the Supplementary Appendix. Once a patient becomes a KPCO Medicare Advantage member, they typically have their own policy linked to only their medical

record number so a family relationship such as spouse is no longer linked by an insurance policy for these members. Therefore, we used membership data from 2005 through 2019 to capture relationships over a longer time period. We matched addresses using membership records of addresses over time. PLWD with addresses for nursing facilities and assisted living locations were excluded since their care is being provided by the institution. Of the 15,755 PLWD, we were able to identify 3446 spousal caregiver-PLWD dyads. Specific steps related to address matching are available in the Supplementary Appendix.

Identification of Analytic Sample of Spousal Caregiver-PLWD Dyads (Fig. 1)

For the 3446 members in the initial matched spousal caregiver-PLWD dyads, we defined periods of overlap to align times when both members were alive, enrolled at KPCO

and both at the matched address based on their individual address start and stop dates. There were 2934 spousal caregiver-PLWD dyads who had positive overlap after considering these requirements. We required a minimum of 1 year prior enrollment for the PLWD to capture comorbidity and prior utilization covariates. This dropped 130 members, leaving $N = 2804$ spousal caregiver-PLWD dyads.

To classify discharge diagnoses into categories, the AHRQ Clinical Classifications Software Refined (CCSR) was applied to the ICD10 primary discharge diagnosis codes.¹⁶

Testing the Validity of the Matching Approach

Last names were examined as one indicator of appropriate matches and among spouses with address matches, ~93% had last names that matched the PLWD. To further test the validity of matching spousal-PLWD dyads, we surveyed a sample of 1000 KPCO members presumed to be the spouse or domestic partner of an identified KPCO member with a diagnosis of dementia identified using the methodology described above. The survey was administered using Research Electronic Data Capture (REDCap) via email or mailed to those without an email and tracked using REDCap from January to May 2022.^{17, 18} The survey specifically asked (1) are you the caregiver of a person living with dementia and if yes, what is your relationship to the person living with dementia. Of the 510 individuals who responded to the survey, 452 (89%) identified as being a spousal caregiver to a person living with dementia. Details of the survey cohort and the analytic sample are provided in Supplementary Appendix Table 2.

Statistical Analyses

Descriptive analyses used *T*-tests or nonparametric Wilcoxon rank sum tests for continuous variables and chi-square for categorical variables. We examined the impact of caregiver hospitalizations on PLWD hospitalizations using Cox proportional hazards models. Caregiver hospitalizations were included as time-varying covariates in counting process models,¹⁹ and only the first 180 days after a caregiver hospitalization were considered as high risk in these analyses. High risk was

identified by a binary variable that reverted to low risk at 181 days following the caregiver hospitalization. A follow-up period began at the earliest point both address and insurance coverage overlapped for a dyad and ended when a PLWD's hospitalization occurred or was censored at disenrollment/death for either the PLWD or caregiver or if address overlap ended. The maximum follow-up was 4 years. Multiple hospitalizations for the same member were retained in the model using the Anderson/Gill method for recurrent events²⁰ with a new follow-up period starting after PLWD hospital discharge when appropriate. In addition to the time-varying indicator for hospitalization of the spousal caregiver in the prior 180 days, adjusted models included PLWD variables for age, gender, race/ethnicity, Charlson Comorbidity Index (CCI), number of hospitalizations, and ED visits in the baseline year. All analyses were performed using SAS software version 9.04 for SAS Studio (SAS Institute, Inc., Cary, NC).

RESULTS

Among the 2804 spousal caregiver-PLWD dyads, the average age of the caregivers was 73 ± 8 years and 75 ± 7 years for PLWD. The majority of caregivers were women (58%) and 58% of the PLWD were men. Most caregivers (78%) and PLWD (78%) were non-Hispanic White.

Nearly half (46%) of all PLWD had at least one hospitalization during the follow-up time period (Table 1), 662 (23.6%) having one and 640 (22.8%) having two or more hospitalizations. There was a total of 2777 hospitalizations (mean number per person was 2.13 ± 1.84 for the 1302 with ≥ 1). Older age, male sex, and a higher CCI score were significantly associated with a greater risk of hospitalization among PLWD ($p < .001$). Having previous hospitalizations and ED visits in the baseline year were also significantly positively associated with an increased risk for hospitalization among PLWD ($p = .001$).

Caregivers had 15.9 hospitalizations per 100 person years and PLWD had 27.5 hospitalizations per 100 person years. Survival analysis demonstrated that a PLWD had a higher risk

Table 1 Characteristics of Persons Living with Dementia by Hospitalization Outcome

	Person living with dementia (PLWD) (N = 2804)		p value*
	Not hospitalized (N = 1502)	Hospitalized (N = 1302)	
Age, mean (SD)	74.2 (7.4)	75.4 (7.3)	< 0.001
Male, n (%)	811 (54%)	806 (62%)	< 0.001
Race/ethnicity, n (%)			0.14
White	1164 (78%)	1017 (78%)	
Nonwhite or Hispanic	315 (21%)	253 (19%)	
Unknown	23 (1.5%)	32 (2.5%)	
Charlson Comorbidity Index (CCI), mean (SD)	2.1 (2.21)	3.0 (2.54)	< 0.001
# hospitalizations in baseline year, mean (SD)	0.14 (0.45)	0.28 (0.70)	< 0.001
# emergency department visits in baseline year, mean (SD)	0.30 (0.72)	0.52 (1.11)	< 0.001

*p value from t-test for age, from Wilcoxon rank sum for CCI, # hospitalizations and # emergency department visits, and from chi-square test for gender and race/ethnicity

of hospitalization if their spousal caregiver was hospitalized in the previous 180 days. This result persisted when controlled for other factors (Fig. 2). Of the 172 admissions among PLWD that occurred within 180 days of a caregiver hospital admission, the most common CCSR for the principal discharge diagnoses were diseases of the circulatory system (20%), certain infectious and parasitic diseases (17%), and diseases of the digestive system (11%).¹⁶

DISCUSSION

In this initial study of linking spousal caregivers to PLWD from the EHR, we found that a caregiver hospitalization was significantly associated with an increased risk of hospitalization for PLWD in the subsequent 180 days. The results indicate that the outcomes for the spousal caregiver-PLWD dyads living in the same household may be associated. The impact of the caregiver’s condition is known to affect a PLWD. Amjad et al. reported an increased risk of hospitalization for older adults with dementia (when cared for by a family member or unpaid caregiver) based on caregiver characteristics such as caregiver physical strain, a shorter total duration of caregiving, and providing more hours of caregiving weekly.²¹ However, the impact of hospitalization of the caregiver on the PLWD was not assessed. This work contributes to the increasing evidence that the health of a caregiver impacts the PLWD they care for. It may be important for interventions designed to improve outcomes for PLWD to take the caregiver into account.

Identification of high-risk time periods that result in the “break-up” of the dyad can better target and tailor interventions to support the dyad and mitigate disruption in the spousal-caregiver relationship. Studies have assessed the caregiver-care-recipient health care utilization using longitudinal survey data.^{4, 21–24} However, there is a need to use health care data for both a caregiver and a PLWD to assess the impact the health of one member of the dyad has on the other. Previous research confirms that there are rarely systematic methods used to collect and identify caregivers of PLWD in an EHR.²⁵ A previous study used home- and community-based referral sources to identify unpaid caregivers of Veterans.²⁵ They were able to successfully identify Veterans who had unpaid caregivers using the EHR, but the identification and confirmation of caregivers were labor and resource intensive.²⁵ Other research has used natural language processing (NLP) methods using social work notes in the EHR to determine the marital status of patients.²⁶ While the use of NLP may be useful to identifying individuals’ current marital status, this methodology may not be able to specifically identify the patient’s spouse/partner or link their information to monitor the effect of one spouse’s health care event on the other.²⁶

The linking methodology reported here provides the basis to test the effect of an intervention for one spousal member of the dyad on the other. Interventions that target caregiver wellbeing are important to potentially reduce caregiver hospitalization and prevent subsequent poor outcomes for the PLWD. Health care systems may also be able to create

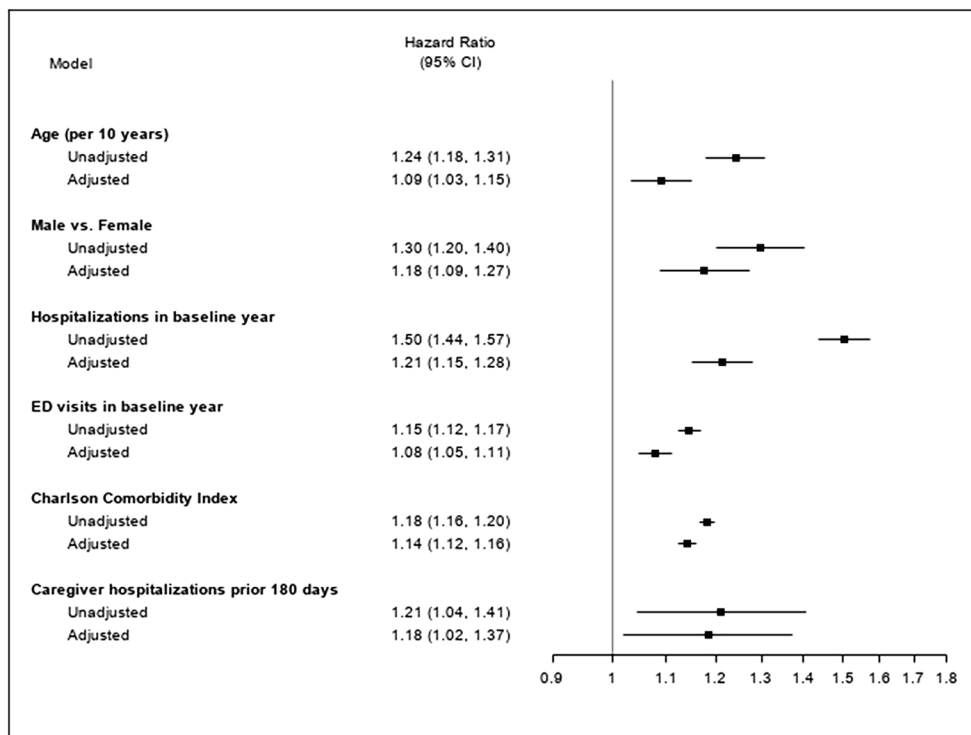


Figure 2 Forest plot of hazard ratios for hospitalization by subgroup: adjusted and unadjusted hazard ratios per subgroup.

interventions to care for PLWD more actively during a caregiver's hospitalization. Caregiver interventions are beneficial for improving caregiver burden, mental health, confidence in caregiving, and self-care, but have rarely been linked to caregiver health care utilization or hospitalization.^{27–29} Managed care plans have a unique opportunity to link data through insurance numbers and to further validate dyad identification. Managed care plans that apply this methodology will gain information regarding the impact of caregiving on their member dyads and prompt the building of interventions that can be applied and outcomes measured for a spousal caregiver-PLWD dyad.

Limitations

We recognize that the role of caregiver for a PLWD is not limited to spouses. Caregivers of PLWD can also include other family members, friends, and paid-caregivers. Also, we understand that not all spouses of a PLWD self-identify as a caregiver or take on that role; for some, this may be because they themselves are in poor health and unable to care for their spouse.⁴ Misclassification due to selected spousal-dyads not being caregivers or potentially having additional caregivers within the household would likely have biased our results towards the null.

Our data are also limited in the ability to capture LGBTQ spouses/partners; sexual orientation/transgender are difficult to link and presently not well documented in our EHR. Identification of these dyads requires further exploration.

This linking approach is not all inclusive. For example, we missed linking spouses never enrolled together under one ID and errors in address matching likely dropped some spouses who lived together. However, there is no reason to believe that those that are missed due to difficulty in matching or missing data should be different than the identified dyads.

We examined a set risk period of 180 days following a caregiver hospitalization. Future studies to identify time periods of highest risk could be useful.

CONCLUSION

This work demonstrates that PLWD are at an increased risk for hospitalization following the hospitalization of a spousal caregiver. This methodology from a Medicare Advantage plan provides an approach to linking spousal caregivers and PLWD allowing for identification of optimal timing of interventions to support spousal dyads. This work provides the methodological basis for future tests of spousal dyad interventions.

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Declarations:

Conflict of Interest: All authors have no conflicts of interest regarding this work.

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