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Patterns of Care Partner Communication for Persons Living with Dementia in the Emergency Department

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ABSTRACT

Introduction	Nearly half of all persons living with dementia (PLWD) will visit the emergency department (ED) in any given year and ED visits by PLWD are associated with short-term adverse outcomes. Care partner engagement is critical in the care of PLWD, but little is known about their patterns of communication with ED clinicians.
Methods	We performed a retrospective electronic health record (EHR) review of a random sampling of patients ≥ 65 years with a historical diagnosis code of dementia who visited an ED within a large regional health network between 1/2014 and 1/2022. ED notes within the EHRs were coded for documentation of care partner communication and presence of a care partner in the ED. Logistic regression was used to identify patient characteristics associated with the composite outcome of either care partner communication or care partner presence in the ED.
Results	A total of 460 patients were included. The median age was 83.0 years, 59.3% were female, 11.3% were Black, and 7.6% Hispanic. A care partner was documented in the ED for 22.4% of the visits and care partner communication documented for 43.9% of visits. 54.8% of patients had no documentation of care partner communication nor evidence of a care partner at the bedside. In multivariate logistic regression, increasing age (OR, (95% CI): 1.06 (1.04-1.09)), altered mental status (OR: 2.26 (1.01-5.05)), and weakness (OR: 3.38 (1.49-7.65)) significantly increased the probability of having care partner communication documented or a care partner at the bedside.
Conclusion	More than half of PLWD in our sample did not have clinician documentation of communication with a care partner or a care partner in the ED. Further studies are needed to use these insights to improve communication with care partners of PLWD in the ED.

INTRODUCTION

In 2019, an estimated 5.8 million people in the United States were affected by Alzheimer's disease and Alzheimer's disease related dementias (AD/ADRD), a number expected to rise to 13.8 million by 2050.¹ Persons living with dementia (PLWD) represent an important and growing emergency department (ED) demographic with studies suggesting nearly half of PLWD visit the ED in any given year.² PLWD visit the ED more frequently, present with more comorbidities, and have higher 30 day return rates than patients without dementia.^{2,3} For these reasons, improving emergency care for PLWD has become a key national objective.⁴

Multiple barriers to effective communication exist in the ED, including limited opportunities for interaction with the healthcare team, high emotional stress, a chaotic environment, and limited privacy. Poor communication has been highlighted as a major barrier in ED care transitions of PLWD, contributing to the increased risk of adverse outcomes.⁵ PLWD are also less likely to understand ED

diagnosis and instructions⁶ and may require greater accommodations than other patients to meet their basic care, safety, and information needs.⁷

Among adults over the age of 50 in the US, 16.8% receive care from an estimated 41.8 million adult caregivers.⁸ Dementia care in the ED often involves the “dyad” of the PLwD and their care partners, making it important to understand engagement of both patients and their care partners. Geriatric ED Guidelines recommend that discharge protocols facilitate communication of relevant information to patients, families, and outpatient care providers, including nursing homes.^{8,9} In studies that assessed communication with PLwD in hospital care, care partners reported insufficient involvement in care planning for PLwD and stressed the need for increased communication from healthcare providers in order to fulfill their roles as care partners.^{5,10} Themes of care partner dissatisfaction with their inclusion in treatment discussion are consistent throughout qualitative studies. However, little research has been conducted to quantify engagement with care partners or determine the identity of care partners present during ED visits.¹⁰

To address this knowledge gap, this study aims to identify patterns of care partner communication for PLwD in the ED. In particular, we aim to describe the presence or absence of communication to care partners, patient demographics within care partner communication patterns, and care partner characteristics.

Objective

The primary objective of this study was to describe how often ED clinicians documented the presence of or communication with care partners of PLwD in the electronic health record (EHR).

METHODS

Study Design and Setting

This was a retrospective observational cohort study of ED visits from PLwD from a large New England Health System. The health system includes 9 EDs across Connecticut and Rhode Island with an overall annual census of approximately 500,000 visits, 20% of which is age ≥ 65 . ED visits of patients seen between 1/1/2014 and 1/1/2022 with a history of dementia as captured by diagnosis codes (Supplementary Methods) and age ≥ 65 were included. From the cohort, we selected a random sample of unique ED patient visits, extracting demographics, visit diagnoses, ED disposition, and physician/nursing notes from our central data warehouse. Sampling was performed using the *python* programming language. Our institutional review board approved this study and waived the need for informed consent (HIC# 2000031684).

Manual Electronic Health Record Review Methodology

For each PLwD chart, we asked two questions of the combined physician and nursing notes: “is there evidence of care partner communication with the ED team” and “is there evidence of a care partner present in the ED”? These questions were answered independently as either a yes or no. If either of these were answered affirmatively, we also manually extracted the relationship of the care partner to the patient (e.g., son, daughter, aide, etc.), with multiple care partners able to be recorded for a given encounter. For evidence of care partner communication, we did not require any documentation of the content of the communication. For example, physician documentation that a family member reported a given symptom was accepted as evidence of communication. Each chart was reviewed manually by two blinded reviewers (AG, EG) and discrepancies were reviewed by a third reviewer (ADH). Prior to beginning the review process, multiple study authors (AG, EG, ADH, RAT, CG) reviewed a number of cases together to ensure agreement on coding methods. Levels of agreement between reviewers was measured using Cohen’s kappa for each care partner question independently as well as for the composite outcome.

Statistical Analysis

We powered our study to calculate the proportion of EHRs with evidence of care partner communication with a margin of error of 5%, 95% confidence, and estimating a population proportion of 50% communication. Based on the power analysis, the sample size required >365 charts.

Following EHR documentation review, we performed multiple analyses. We first assessed the proportions of visits with either documented care partner communication or care partner presence. In order to assay for risk factors associated with a lack of care partner contact, we then performed univariate and multivariate logistic regression analyses for the composite outcome of either care partner communication documented or care partner present in the ED. Variables used in regression included patient age, race, ethnicity, presenting complaint, and ED disposition (admit, discharge, or other). We limited presenting complaints to the top nine most common complaints in our cohort with the remainder summarized by “other”. All analyses were performed in Python with the *statsmodels* package.

RESULTS

A total 460 ED visits from unique patients were randomly sampled and extracted with a median age of 83 (interquartile range: 75-89) years of age, 59.3% female, 40.7% White, 11.3% Black, 7.6% identifying as Hispanic or Latino. 92.6% had Medicare as their primary insurance. Falls (20.0%), shortness of breath (9.8%), and altered mental status (8.0%) were the most common chief complaints and a majority of ED visits resulted in admission (57.8%). Study demographics are shown in Table 1.

Table 1: Study demographics

		Overall	Communication and/or Presence	No Communication or Presence	P-Value
n		460	208	252	
Age, median [Q1,Q3]		83.0 [75.0,89.0]	85.0 [78.0,91.0]	80.0 [73.0,88.0]	<0.001
Sex, n (%)	Female	273 (59.3)	120 (57.7)	153 (60.7)	0.575
	Male	187 (40.7)	88 (42.3)	99 (39.3)	
Race, n (%)	White or Caucasian	369 (80.2)	164 (78.8)	205 (81.3)	0.709
	Black or African American	52 (11.3)	24 (11.5)	28 (11.1)	
	Other	39 (8.5)	20 (9.6)	19 (7.5)	
Ethnicity, n (%)	Non-Hispanic	420 (91.3)	189 (90.9)	231 (91.7)	0.399
	Hispanic or Latino	35 (7.6)	18 (8.7)	17 (6.7)	
	Unknown	5 (1.1)	1 (0.5)	4 (1.6)	
Insurance, n (%)	Medicare	426 (92.6)	193 (92.8)	233 (92.5)	0.759
	Medicaid	16 (3.5)	6 (2.9)	10 (4.0)	
	Other	18 (3.9)	9 (4.3)	9 (3.6)	
ED Disposition, n (%)	Admit	266 (57.8)	122 (58.7)	144 (57.1)	0.942
	Discharge	172 (37.4)	76 (36.5)	96 (38.1)	
	Other	22 (4.8)	10 (4.8)	12 (4.8)	
AMS, n (%)		37 (8.0)	24 (11.5)	13 (5.2)	0.015
Falls, n (%)		292 (20.0)	45 (21.6)	47 (18.7)	0.429
Shortness of Breath, n (%)		45 (9.8)	18 (8.7)	27 (10.7)	0.456
Weakness, n (%)		35 (7.6)	25 (12.0)	10 (4.0)	0.002
Abdominal Pain, n (%)		28 (6.1)	8 (3.8)	20 (7.9)	0.060
Chest Pain, n (%)		23 (5.0)	6 (2.9)	17 (6.7)	0.050
Dizziness, n (%)		16 (3.5)	9 (4.3)	7 (2.8)	0.378
Hip Pain, n (%)		15 (3.3)	6 (2.9)	9 (3.6)	0.678
Back Pain, n (%)		14 (3.0)	3 (1.4)	11 (4.4)	0.057
Other Chief Complaint, n (%)		299 (65.0)	130 (62.5)	169 (67.1)	0.310

There was good agreement between the primary reviewers on the composite outcome of either care partner communication or presence in the ED ($\kappa = 0.74$). For the individual components, there was good agreement for documentation of care partner communication ($\kappa = 0.72$), and fair agreement on presence of a care partner in the ED ($\kappa = 0.34$). After adjudication, we observed that a care partner was documented at bedside for 22.4% of patients; care partner communication was documented for 43.9% of visits; and 54.7% of visits had neither care partner communication or care partner presence in the ED documented. Across chief complaints, rates of the composite outcome of documentation of either care partner communication or presence in the ED was higher for weakness (71.4%) and altered mental

status (64.9%) and lower for chest pain (26.1%) and back pain (21.4%). The most prevalent care partners were daughters (35.9%), sons (21.2%), family (nonspecific) (18.2%), wives (14.7%), and husbands (7.7%) with female care partners more commonly documented than male (54.1% female, 29.4% male, 24.7% unknown) (Figure 1). Aides and nurses comprised a small percentage of visits (4.1%).

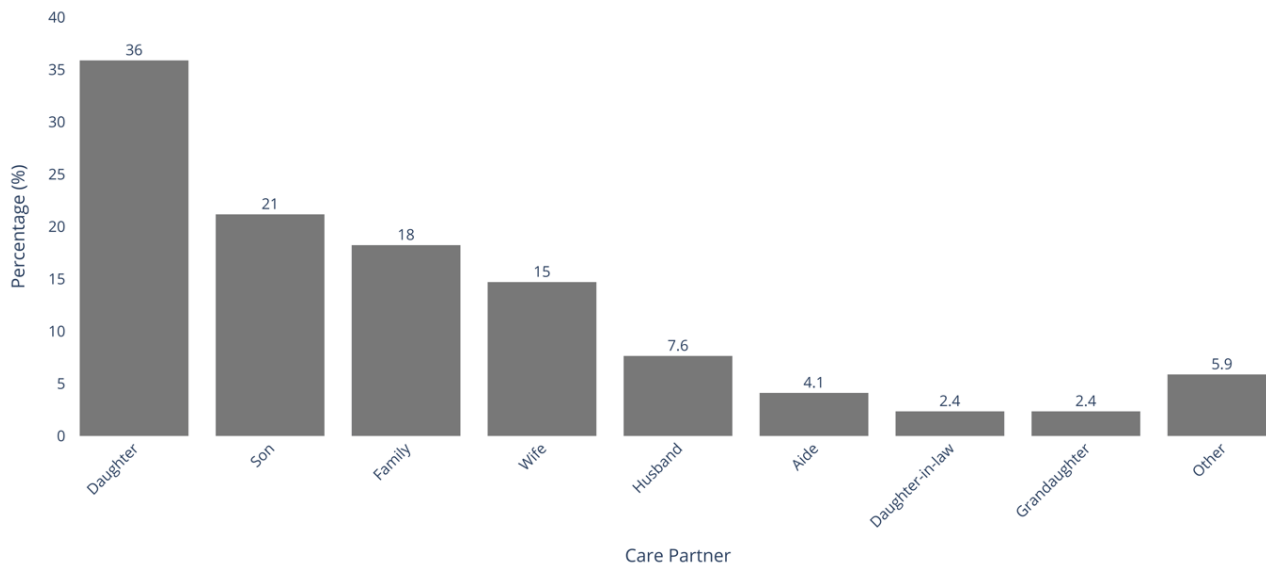


Figure 1. Documented care partners of persons living with dementia in the ED.

In univariate analysis of the composite outcome, older age (OR: (95% CI); 1.05 (1.03-1.08)), and chief complaint of weakness (OR: 3.31 (1.55-7.06)) or AMS (OR: 2.40 (1.19-4.84)) were associated with increased likelihood of documentation of either care partner communication or care partner presence in the ED. In multivariate analysis, older age (1.06 (1.04-1.09)), chief complaint of weakness (OR: 3.38 (4.49-7.65)), or AMS (OR: 2.26 (1.01-5.05)), increased the likelihood of the composite outcome. None of the adjusted odds ratios were significantly inversely related to the composite outcome.

Table 2: Univariate and multivariate regression models predicting composite outcome of lack of documented care partner communication or presence in the ED.

Table 2: Univariate and multivariate regression models predicting composite outcome of lack of documented care partner communication or presence in the ED.

		Univariate OR (95% CI)	p-value	Multivariate OR (95% CI)	p-value
Demographics					
	Age	1.05 (1.03-1.08)	5.54E-07	1.06 (1.04-1.09)	8.16E-07
	Male (ref. Female)	1.13 (0.78-1.65)	0.046	1.34 (0.89-2.04)	0.162
Race					
	Black or African American (ref. White or Caucasian)	1.07 (0.60-1.92)	0.033	1.33 (0.70-2.56)	0.385
	Other (ref. White or Caucasian)	1.32 (0.68-2.55)	0.033	1.26 (0.45-3.49)	0.662
Ethnicity					
	Hispanic or Latino (ref. Non-Hispanic)	1.29 (0.65-2.58)	0.041	1.96 (0.65-5.89)	0.233
	Unknown (ref. Non-Hispanic)	0.31 (0.03-2.76)	0.041	0.40 (0.04-3.93)	0.435
Insurance					
	Medicaid (ref. Medicare)	0.72 (0.26-2.03)	0.053	1.03 (0.32-3.29)	0.966
	Other (ref. Medicare)	1.21 (0.47-3.10)	0.053	1.71 (0.60-4.89)	0.318
Disposition					
	Discharge (ref. Admit)	0.93 (0.64-1.37)	0.178	1.08 (0.69-1.68)	0.733
	Other (ref. Admit)	0.98 (0.41-2.36)	0.178	1.13 (0.41-3.11)	0.819
Chief Complaints					
	Weakness	3.31 (1.55-7.06)	0.004	3.38 (1.49-7.65)	0.003
	Altered Mental Status	2.40 (1.19-4.84)	0.008	2.26 (1.01-5.05)	0.048
	Chest Pain	0.41 (0.16-1.06)	0.115	0.39 (0.14-1.12)	0.080
	Back Pain	0.32 (0.09-1.16)	0.089	0.28 (0.07-1.16)	0.080
	Abdominal Pain	0.46 (0.20-1.08)	0.124	0.53 (0.20-1.36)	0.187
	Dizziness	1.58 (0.58-4.33)	0.029	1.57 (0.51-4.80)	0.430
	Shortness of Breath	0.79 (0.42-1.48)	0.086	0.74 (0.35-1.56)	0.432
	Other	0.82 (0.56-1.20)	0.694	0.85 (0.51-1.41)	0.519
	Falls	1.20 (0.76-1.90)	0.029	1.18 (0.66-2.08)	0.581
	Hip Pain	0.80 (0.28-2.29)	0.052	0.81 (0.26-2.58)	0.727

DISCUSSION

To the best of our knowledge, this is the first study to describe the frequency of documented communication between ED clinicians and the care partners of PLwD. In this retrospective observational cohort study, over half of the visits of PLwD did not have documentation of either a care partner present in the ED or of care partner communication by an ED clinician. PLwD were more likely to have care partner communication or presence in the ED if they were older or presenting with complaints of altered mental status or weakness. The most common care partners were children (sons or daughters), and female care partners were more common than male.

This study expands on prior qualitative reports that revealed themes of dissatisfaction with care partner communication and involvement in care planning in the inpatient setting. Care partner engagement and communication by and with ED staff is critical, particularly in the population of PLwD given unique considerations that promote success or lead to failure with ED-to-community care transitions.^{5,11,12} In particular, PLwD may have more difficulty providing key details regarding the events preceding their ED presentations or their medical histories. Moreover, prior studies have noted an association between cognitive impairment and poor comprehension of ED diagnosis, anticipated course of illness, and return precautions.¹⁰ For these reasons, clinician communication with care partners is critical during all phases of ED care. We propose that the association between communication and patient-centered outcomes is an important area for future research.

The minority of care provided by aides and nurses in our study sample mirrors prior epidemiologic analyses of persons with and without AD/ABD that showed a majority rely on family care partners.¹³ In cases where the identity of care partners were documented, we observed a trend towards female predominance with first generation children the most often represented. These findings echo a recent study of the family confusion assessment method which identified a trend towards spouses

and women as the care partners of older adults in the ED.¹⁴ There is increasing appreciation of the prevalence of care partner burden defined as physical, emotional, or financial hardship which has been reported to be more than 50% in some studies.¹⁵ Adult child, female care partners, and those providing care to PLwD are at particular risk for care partner burden. The predominance of those demographics in our study suggests that the ED may be a unique setting in which to try to help mitigate care partner burden risk.

Limitations

Our study of ED care partner communication included manual chart review, but it is likely that there are undocumented events leading to underestimation of rates of care partner presence and communication. Moreover, our chart review methodology did not allow us to assess for differences among patients with varying disease burdens of AD/ADR. We hypothesize there may be communication differences between early-stage and late-stage PLwD affecting care partner involvement. The data used in this study is from a random sample of ED visits from one healthcare system within a limited geographical area and may not be generalizable to other healthcare settings. Additionally, the date range of the cohort includes the COVID-19 pandemic, which may affect the presence of care partners though visitors were permitted for PLwD.

CONCLUSION

A majority of the sampled ED visits by PLwD did not have documentation of care partners at the bedside or communication between the ED team and a care partner. There is limited literature in this space and further studies are needed to externally validate these findings. These results highlight the need for interventions to promote effective care partner communication in the ED.

KEYWORDS

Dementia, emergency department, communication, care partners, geriatrics

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CONFLICTS OF INTEREST

The authors report no conflicts of interest.

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Author Contributions: ADH and RAT designed the study. ADH, AG, EG, LC, and RAT acquired, analyzed, and interpreted the data. ADH, AG, LC, CG, and RAT drafted the manuscript. ADH, CG, MS, UH, and RAT provided critical revisions.

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