

The Center for Home Care Policy & Research, established in 1993, conducts scientifically rigorous research to promote the delivery of high-quality, cost-effective care in the home and community. To date, the Center has been awarded over \$59 million in federal and private grant and contract funding, evolving into a multi-functional scientific research and evaluation team informing VNS Health, local, national, & international health policy, science & evidence-based practice.

GRANT PROPOSAL EFFORTS.

16 new proposals submitted in 2022 (12 federal), total of \$5,991,026 in requested funding

- To date, **6** proposals awarded funding (3 Federal awards); total value of \$340,312
- 8 submissions still under consideration

NEW PROPOSAL SUBMISSIONS since November 2022 committee meeting.

- National Institute on Aging (NIA) UPenn P30 pilot (**Zolnoori**) *A speech-processing algorithm for automatic screening of Black patients with mild cognitive impairment and early dementia in the home healthcare setting* (\$241,649)
- National Institute of Nursing Research (NINR) R21(**Riegel**) Refining a virtual health coaching intervention to improve self-care of caregivers (\$471,103)

NEW RESEARCH AWARDS since November 2022 committee meeting.

- NJ ACTS Pilot Program (Rutgers University) (Luth/**Bowles**) *Translating Data Science to Palliative Care Practice: Improving Integration of a Claims-Based Algorithm and Palliative Care Uptake* (\$21,496) **Aims:** 1. Engage palliative care experts to document their decision-making processes and identify factors important in determining palliative care eligibility and useful formats for integrating algorithm results into practice; 2. Empirically test if feedback from Aim 1 is consistent with current practice using multivariate logistic regression analyses.; 3. Complement existing 12-month mortality algorithm with a second model that discriminates between geriatric members and those needing palliative care.
- Mother Cabrini Health Foundation (2023 Continuation of CHCPR Evaluation) (Veteran's program liaison/**Stern**) *VNS Health Veterans Outreach Project* (\$23,459) The Research Center's role in this project is to provide data collection support and conduct an evaluation of the Veteran Liaison Program, which strives to expand healthcare access to veterans and their families; assist veterans in accessing benefits and community resources to ensure they are receiving the care and services to which they are entitled; help bridge the transition into the community from in-patient facility settings; and provide educational sessions for nurses, social workers, and home health aides to sensitize them to the special needs of veteran patients.
- National Institute on Aging (NIA) (Murali/**McDonald**) *IMPACT Collaboratory: Barriers to Hospice Care Transitions for Diverse Persons Living with Dementia (PLWD)*(\$7,000) **Aims:** 1. Explore perspectives of care partners, home health staff (HHC) and providers about barriers to hospice transitions for racially and ethnically diverse PLWD; 2. Survey care partners, HHC staff, and providers about key components of a transitional care checklist intervention that will guide hospice transitions for diverse PLWD; 3. Design a novel culturally sensitive hospice transitions checklist to guide transitional care to hospice from HHC for PLWD and their care partners.

EXTERNALLY FUNDED RESEARCH & EVALUATION STUDIES. **33** active studies in 2022

PEER-REVIEWED PUBLICATIONS & PRESENTATIONS. In 2022, **33** manuscripts published (7 since November 2022 committee meeting); **6** additional already in 2023. **5** more currently under review. **30** Presentations

Original Manuscript

Clinical and Demographic Profiles of Home Care Patients With Alzheimer's Disease and Related Dementias: Implications for Information Transfer Across Care Settings

Miriam Ryvicker^{1,2}, Yolanda Barrón¹, Shivani Shah¹, Stanley M. Moore¹, James M. Noble², Kathryn H. Bowles^{1,4}, and Jacqueline Merrill¹

Abstract

Home health care (HHC) clinicians serving individuals with Alzheimer's disease and related dementias (ADRD) do not always have information about the person's ADRD diagnosis, which may be used to improve the HHC plan of care. This retrospective cohort study examined characteristics of 56,652 HHC patients with varied documentation of ADRD diagnoses. Those included clinical assessments and Medicare claims from 6-month look-back period used a novel definition. Months half the



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BRIEF REPORT

Impact of diagnosed (vs undiagnosed) dementia on family caregiving experiences

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OXFORD

Research Article

"Care for Me, Too": A Novel Framework for Improved Communication and Support Between Dementia Caregivers and the Home Health Care Team

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Abstract

Background: Most older adults with Alzheimer's disease and related dementias (ADRD) do not receive a timely formal diagnosis, although formal diagnosis is linked to improved outcomes. Little is known about how a recognized formal diagnosis impacts family caregivers, who provide crucial support for older adults experiencing ADRD.

Methods: We analyzed 2017 National Health and Aging Trends Study and linked National Study of Caregiving data for a nationally representative sample of 734 (weighted $n = 5,431,551$) caregivers who assisted an older adult with probable dementia. Probable dementia was determined via previously validated composite measure. We modeled caregiver experiences as a function of recognized formal ADRD diagnosis using weighted, logistic regression and adjusting for the relevant older adult and caregiver characteristics.

Results: Among caregivers who assisted an older adult with probable dementia, those assisting an individual with recognized formal ADRD diagnosis were significantly more likely to report emotional difficulty ($\text{aOR}: 1.77, p = 0.03$).

Ryvicker, M., Barrón, Y., Shah, S., Moore, S., Feldman, P., Noble, J., Bowles, K., Merrill, J. (2022). [*Clinical and demographic profiles of home care patients with alzheimer's disease and related dementias: Implications for information transfer across care settings*](#). *Journal of Applied Gerontology*. 41(2):534-544.

Abstract: Home health care (HHC) clinicians serving individuals with Alzheimer's disease and related dementias (ADRD) do not always have information about the person's ADRD diagnosis, which may be used to improve the HHC plan of care. This retrospective cohort study examined characteristics of 56,652 HHC patients with varied documentation of ADRD diagnoses. Data included clinical assessments and Medicare claims for a 6-month look-back period and 4-year follow-up. Nearly half the sample had an ADRD diagnosis observed in the claims either prior to or following the HHC admission. Among those with a prior diagnosis, 63% did not have it documented on the HHC assessment; the diagnosis may not have been known to the HHC team or incorporated into the care plan. Patients with ADRD had heightened risk for adverse outcomes (e.g., urinary tract infection and aspiration pneumonia). Interoperable data across health care settings should include ADRD-specific elements about diagnoses, symptoms, and risk factors.

Burgdorf, J.G., Amjad, H. (2022: e-published ahead of print). [*Impact of Diagnosed \(versus Undiagnosed\) Dementia on Family Caregiving Experiences*](#). *Journal of the American Geriatrics Society*. 2022;5(2):e34628

Abstract

Background: Most older adults with Alzheimer's disease and related dementias (ADRD) do not receive a timely formal diagnosis, although formal diagnosis is linked to improved outcomes. Little is known about how a recognized formal diagnosis impacts family caregivers, who provide crucial support for older adults experiencing ADRD.

Methods: We analyzed 2017 National Health and Aging Trends Study and linked National Study of Caregiving data for a nationally representative sample of 724 (weighted n = 5,431,551) caregivers who assisted an older adult with probable dementia. Probable dementia was determined via previously validated composite measure. We modeled caregiver experiences as a function of recognized formal ADRD diagnosis using weighted, logistic regression and adjusting for the relevant older adult and caregiver characteristics.

Results: Among caregivers who assisted an older adult with probable dementia, those assisting an individual with recognized formal ADRD diagnosis were significantly more likely to report emotional difficulty (aOR: 1.77; p = 0.03) and family disagreement over the older adult's care (aOR: 5.53; p = 0.03). They were also more likely to assist with communication during doctors' visits (aOR: 9.71; p < 0.001) and to receive caregiving-related training (aOR: 2.59; p = 0.01).

Conclusions: While a timely ADRD diagnosis may help ensure access to needed supports for older adult and caregiver alike, diagnosis must be linked to support as they navigate resultant complex emotions. Formal diagnosis is linked to caregiver integration with, and support from, the older adult's team of health care providers; therefore, reducing existing disparities in timely diagnosis is necessary to ensure all caregivers have equal access to support.

Burgdorf J., Reckrey J., Russell D. (2022: e-published ahead of print). [*'Care for Me, Too': A Novel Framework for Improved Communication and Support between Dementia Caregivers and the Home Health Care Team*](#). *The Gerontologist*. PMID: 36317266.

Abstract

Background and Objectives: Identifying and meeting the needs of family and unpaid caregivers (hereafter, "caregivers") during home health (HH) can improve outcomes for patients with Alzheimer's Disease and Related Dementias (ADRD). However, little is known regarding ADRD caregivers' perspectives on communication and support from the HH care team. The study objectives were to identify ADRD caregivers' common support needs during HH and preferences for addressing these needs, to inform future development of an assessment and support intervention.

Research Design and Methods: We conducted semistructured key informant interviews with caregivers who had recently assisted a HH patient with ADRD (n=27). Interview transcripts were analyzed using directed content analysis.

Results: Caregivers identified four major support needs: assistance navigating insurance and service coverage, training on nursing tasks, referral to respite care, and information regarding ADRD disease progression. Caregivers described major barriers to communicating these needs, including never being directly asked about their needs and information discontinuity within the HH care team. Incorporating caregiver recommendations, we propose a new model of assessment and support in which the HH care team (a) proactively asks about caregiver needs, (b) presents available supportive resources, (c) solicits information regarding the patient's needs and routine, and (d) stores and shares this information within the medical record.

Discussion and Implications: Findings reveal critical gaps in current patterns of support for ADRD caregivers during HH and suggest directions for an assessment and support intervention that explicitly queries caregivers on their capacity and needs, with content tailored to the HH setting.