

Title: Incorporating Caregiver Assessment Data in the Home Health Electronic Health Record: An Embedded Pragmatic Clinical Trial

Authors: Julia G. Burgdorf^a, Julia.burgdorf@vnshealth.org; Margaret V. McDonald^a, Margaret.McDonald@vnshealth.org; Kathryn H. Bowles^{a,b}, bowles@nursing.upenn.edu

(a) Center for Home Care Policy & Research, VNS Health

(b) University of Pennsylvania School of Nursing

Abstract body:

Background: One-third of skilled home health (HH) patients have dementia¹, and these patients often require family caregiver assistance to implement the home health plan of care.² Prior work suggests that caregivers are inadequately supported during home health, contributing to poorer clinical outcomes and lower patient/family satisfaction.³⁻⁷ Major obstacles to integrating caregiver support in home health clinical workflows include (1) a lack of systematic capture of caregiver needs within the Electronic Health Record (EHR) and (2) limited access to social work services.^{4,8,9} Home health researchers, administrators, and frontline clinicians created the Dementia Caregivers' Link to Assistance and Resources (DECLARE) via user-centered co-design. DECLARE includes assessment of caregiver burden, tasks, and relationship to the patient, with results stored in the EHR as a care coordination note, and targeted social work referrals for eligible cases.

Objectives: DECLARE is currently being piloted in an embedded Pragmatic Clinical Trial within a major HH agency to assess for feasibility and acceptability. Key outcomes include rate of assessment completion, ability to automatically populate caregiver information in the EHR, and social work access (feasibility) and staff ratings of assessment relevance to care planning (acceptability).

Methods: Treatment is assigned at the clinical team level. Eligible caregivers are those assisting a patient with a dementia diagnosis who are over 18 and comfortable communicating in English. Potentially eligible caregivers are contacted by phone to determine eligibility, enroll, and complete an initial assessment. Assessment results are then automatically uploaded, via Application Programming Interface, into a care coordination note in the EHR. Outcomes are measured from agency claims and clinical note data, and staff surveys and interviews.

Results: Of 248 potentially eligible caregivers identified in the Treatment arm, 34 were ineligible upon initial screening and 76 were unreachable within the 5 days after admission. Of the remaining 138 caregivers, 57% (78) completed the assessment with a mean (SD) of 5.8 (3.0) days between admission and upload of the caregiver assessment information to the patient record (upload occurred automatically the day after assessment completion). Among the 220 caregivers enrolled (n=58 DECLARE, n=142 usual care), those receiving DECLARE had higher rates of social work access (74% vs 28%; p<0.01) and received a social work visit earlier in the episode (9 days after admission vs 13, p=0.01).

Among clinicians surveyed who cared for 1+ DECLARE cases (n=30), 77% (n=23) did not view the coordination note, with most stating they were unaware this information was available. Of those who did view the note (n=7), all agreed that the information was accurate and relevant to the case and 6 of 7 agreed that the information impacted their approach to the case. In key informant interviews, clinicians reported that they were unaware of the DECLARE note as they review all notes prior to their first visit to the home. Clinicians suggested capturing caregiver assessment information during intake and including this information in the intake note, posted prior to the first visit, and/or creating an alert in the EHR that reminds clinicians of the DECLARE note and requires acknowledgement before they can access the main patient record for that case.

Discussion: DECLARE was feasible, with acceptable rates of assessment completion and meaningful improvement in social work access for treatment cases. While caregiver assessment information was rated as accurate and relevant by those who reviewed it, modifications to the protocol are necessary to increase visibility in the patient record. Future research is needed to understand how this information may impact care planning and, ultimately, patient and caregiver outcomes.

Conclusions: Home health clinicians endorse the value of additional information about caregivers but need this information available at Start of Care and stored in structured fields within the EHR.

References

1. Alzheimer's Association. *2025 Alzheimer's disease facts and figures*. 2025. Accessed 4/13/26.
<https://www.alz.org/getmedia/ef8f48f9-ad36-48ea-87f9-b74034635c1e/alzheimers-facts-and-figures.pdf>
2. Burgdorf J, Arbaje A, Wolff J. Older adult factors associated with identified need for family caregiver assistance during home health care. *Home Health Care Manag Pract*. 2019.
doi:10.1177/1084822319876608
3. Burgdorf JG, Wolff JL, Barrón Y, Amjad H. Dementia severity associated with unmet caregiving needs during skilled home health care. *J Appl Gerontol*.
2025;0(0):07334648251332232. doi:10.1177/07334648251332232
4. Burgdorf JG, Arbaje AI, Wolff JL. Training needs among family caregivers assisting during home health, as identified by home health clinicians. *J Am Med Dir Assoc*. 2020.
doi:10.1016/j.jamda.2020.05.032
5. Burgdorf JG, Reckrey J, Russell D. "Care for me, too": a novel framework for improved communication and support between dementia caregivers and the home health care team. *Gerontologist*. 2023;63(5):874-886. doi:10.1093/geront/gnac165
6. Burgdorf JG, Arbaje AI, Stuart EA, Wolff JL. Unmet family caregiver training needs associated with acute care utilization during home health care. *J Am Geriatr Soc*. 2021.
doi:10.1111/jgs.17138
7. Chase J, Russell D, Rice M, Abbott C, Bowles K, Mehr D. Caregivers' experiences regarding training and support in the post-acute home health-care setting. *J Patient Exp*. 2019.
doi:10.1177/2374373519869156
8. Burgdorf JG, Arbaje AI, Chase JA, Wolff JL. Current practices of family caregiver training during home health care: a qualitative study. *J Am Geriatr Soc*. 2021. doi:10.1111/jgs.17492

9. Burgdorf JG, Wolff JL, Chase JA, Arbaje AI. Barriers and facilitators to family caregiver training during home health care: a multisite qualitative analysis. *J Am Geriatr Soc.* 2022.
doi:10.1111/jgs.17762