



Published in final edited form as:

J Am Geriatr Soc. 2022 January ; 70(1): 218–227. doi:10.1111/jgs.17492.

Current Practices of Family Caregiver Training during Home Health Care: A Qualitative Study

Julia G. Burgdorf, PhD^a, Alicia I. Arbaje, MD, MPH, PhD^b, Jo-Ana Chase, APRN-BC, PhD^c, Jennifer L. Wolff, PhD^{a,b}

^aDepartment of Health Policy & Management, Johns Hopkins Bloomberg School of Public Health

^bDivision of Geriatric Medicine and Gerontology, Johns Hopkins University School of Medicine

^cSinclair School of Nursing, University of Missouri

Abstract

Background: Home health clinicians report a need for family caregiver assistance during the majority of skilled home health care episodes. Since 2018, the Medicare Conditions of Participation has required home health agencies to provide training to family caregivers. However, little is known regarding current practices of family caregiver assessment and training during home health care.

Methods: Qualitative research relying on semi-structured key informant interviews with Registered Nurses and Physical Therapists (n=19), hereafter “clinicians”, from four home health agencies. Interviews were recorded and transcribed, then analyzed using directed content analysis to identify relevant themes and concepts.

Results: Three agencies were not-for-profit and one was for-profit; three were urban and one was rural; two operated on a local scale, one on a regional scale, and one on a national scale. Key informants had an average of 9.3 years of experience in home health care and an average age of 45.0 years. Clinicians described a cyclic process of family caregiver training including four major phases: initial assessment, education, reassessment, and adjustment. Initial assessment was informal and holistic; education was delivered via demonstration and teach-back; reassessment was used to evaluate caregiver progress and inform adjustments to the care plan. Clinicians noted that their perceptions regarding the success of family caregiver training efforts influenced decisions relating to clinical practice, including the number of visits provided and whether to discharge the patient.

Conclusions: Caregiver training is currently integrated into clinician workflows in home health care and helps determine visit intensity and discharge timing, but clinicians face a lack of structured assessment instruments or training materials. Efforts by policymakers and home health

CORRESPONDING AUTHOR: Julia G. Burgdorf; Julia.burgdorf@jhu.edu; twitter: @JuliaBurgdorf; mailing address: 29 Coddington Grove, Pittsford NY, 14534.

Author contributions: Burgdorf: study concept and design, data analysis and interpretation, manuscript drafting and preparation. Arbaje: data interpretation, manuscript editing. Chase: manuscript editing. Wolff: study supervision, data interpretation, manuscript editing.

Conflicts of interest: Authors have no conflicts of interest to disclose.

Sponsor's role: No sponsor had any role in study design, data analysis and interpretation, or manuscript preparation.

agencies to facilitate clinicians' training efforts could positively affect the cost and quality of Medicare-funded home health care.

Keywords

Medicare; Care Partners; Family Caregivers; Caregiving; Home Health Care; Education; Home Care Agencies; Home Health Nursing

INTRODUCTION

The Medicare home health benefit provides skilled nursing, therapy, and personal care services in the home setting for eligible beneficiaries who are homebound and require temporary skilled nursing and rehabilitation. Services are delivered via visits from a multidisciplinary team led by a Registered Nurse or Physical Therapist. Among Medicare beneficiaries who are hospitalized, nearly 1 in 3 are referred to post-acute home health care for services such as wound care, medication management, and rehabilitation therapy.¹ In 2019, 3.3 million older adults accessed Medicare-funded home health, and utilization has grown steadily over the past decade.¹ Medicare beneficiaries who access home health are more socially vulnerable and clinically complex, compared to the overall Medicare population.² As a result of patients' complex care needs and intermittent staff presence in the home, home health providers often rely on patients' family and unpaid caregivers to help enact the plan of care. In 87% of Medicare home health episodes, family caregiver assistance is required in addition to care provided by home health agency staff.³

The majority of family caregivers for older adults report feeling unprepared for their caregiving role⁴ and just 1 in 10 receive role-related training.⁵ An emerging body of research suggests that training family caregivers, including offering access to educational materials and instruction in caregiving-related skills such as medication management, wound care, and symptom monitoring, can reduce caregiver burden, increase caregiver efficacy, and positively impact older adults' health outcomes.^{4,6-8} During home health, family caregivers assist with complicated activities ranging from care coordination to wound care^{3,9} and 1 in 3 have an identified need for training in order to successfully provide this assistance.¹⁰ Meeting family caregivers' training needs during home health may help reduce costs of care¹¹ and patients' risk of hospitalization;¹² a particularly salient goal as home health has the highest hospitalization rate of any post-acute setting for Medicare beneficiaries.¹

The Centers for Medicare and Medicaid Services updated the Home Health Conditions of Participation in 2018 to include a requirement that home health agencies provide training and education to family caregivers, as needed to implement the plan of care.¹³ However, no accompanying guidance was issued regarding the recommended modality, frequency, or content of such training. Indeed, little is known regarding current practices of training for family caregivers. A stronger foundational understanding of current practices of family caregiver training during home health is necessary to inform potential policy action and intervention development that could support home health clinicians' efforts in this area and improve outcomes for older adults in this setting.

Using semi-structured key informant interviews with clinicians from a diverse set of home health agencies, we describe how family caregiver training is currently integrated into Medicare-funded home health. We present clinicians' perspectives on the importance of family caregiver training during skilled home health and describe approaches to assessing family caregivers' training needs and providing family caregiver training in this setting. Findings identify areas for improvement and potential actions from both policymakers and providers to better support these efforts.

METHODS

This is a qualitative study relying on semi-structured, in-depth key informant interviews. Interviews were recorded and transcribed, then analyzed using directed content analysis to identify relevant themes and concepts.

Research Team

The interdisciplinary interview and analysis team included four members: two health services researchers with extensive knowledge of family caregiving for older adults and Medicare-funded home health, a geriatrician and health services researcher, and a nurse researcher, both of whom have expertise in qualitative research in the home health setting. Team members had no prior relationships with any of the key informants. The study protocol was approved by the Johns Hopkins Bloomberg School of Public Health Institutional Review Board (IRB #12187) and we followed the Consolidated Criteria for Reporting Qualitative Research.¹⁴

Participants

The study team contacted eight home health agencies for potential inclusion in this research. Four agencies agreed to participate, three declined to participate given the additional time pressures on their staff as a result of the COVID-19 pandemic, and one did not respond. Agencies were purposively selected to obtain variation in geographic region, rurality, ownership structure (for-profit vs non-profit), and scale of operations. The study PI contacted leadership at each organization to describe study aims and request organizational participation and access to members of clinical staff. Each participating agency furnished a list of clinicians who might be willing to participate, along with their contact information. Clinicians were contacted individually via email to ascertain their willingness to be interviewed for our study and to schedule telephone interviews; 23 clinicians were contacted and 19 were ultimately interviewed. Each clinician respondent was sent a \$50 gift card following participation in the study.

Clinician key informants (n=19) included Registered Nurses (RNs) and Physical Therapists (PTs). Recruitment focused on RNs and PTs as these clinicians lead the home health team and only individuals with these licensures may complete the Outcome and Assessment Information Set (OASIS), a standardized patient assessment which, until a 2019 revision, was the only national source of data on caregiver training needs during home health.¹⁵ All RNs and PTs employed by the participating agencies who spoke English were eligible to participate. Recruitment and data collection continued until theoretical saturation was

reached. Theoretical saturation refers to the point at which collection of additional data does not yield new insights related to the research question;^{16,17} one way to operationalize this concept is by monitoring for informational redundancy¹⁸—when new data collection (interviews) does not introduce new themes (suggest additional codes), but rather supports existing themes identified in previous data collection.

Data Collection

Prior studies examining the role of family caregivers during home health suggest the importance of structural factors (e.g. agency training resources, staffing), interpersonal factors (e.g. communication and trust between caregiver/clinician or caregiver/older adult), and individual factors (e.g. caregiver education level, severity of patient care needs) as meaningful determinants of caregiver interactions with the care team.^{3,9,10,19-26} Based on this existing literature and on our study team's content expertise, we developed a conceptual framework (Figure 1) to guide our study. This framework recognizes the importance of these three categories—structural, interpersonal, and individual—and posits how they may interact to affect family caregiver training during home health. The conceptual framework served as a starting point for our semi-structured interview guide (Supplemental Material, section A) and helped guide our data analysis by suggesting initial content code domains.

We created a semi-structured interview guide (Supplementary Material, section A) to solicit information relating to our primary research questions: 1) Do clinicians view family caregiver training as an important component of home health? 2) How do clinicians identify family caregiver training needs? 3) If needs are identified, how are they met/how is training provided? Using this guide, we conducted semi-structured interviews asking primary questions followed by probing questions to solicit greater depth of information and/or clarify responses. Interviews were conducted via telephone between August and October 2020 and ranged from 30-60 minutes in duration. Interviews were audio-recorded and de-identified recordings were transcribed by a HIPAA-compliant transcription service.

Data Analysis

We used directed content analysis to identify themes related to our research questions. In directed content analysis, researchers rely on theory to develop an initial coding template, then revise this template as analysis progresses to reflect concepts and themes that emerge in the data.^{27,28} Codes are labels assigned to sections of text to formally catalogue key concepts while preserving the context in which these concepts emerged.^{16,27-29} We created initial overarching content codes and subcodes informed by our conceptual framework, then used a semantic approach to coding by adding codes that emerged from explicit statements by participants, but were not anticipated by our conceptual framework.²⁸

The coding template was iteratively adjusted throughout the analysis phase of this research through team discussions. Two study team members (JGB, AIA) independently reviewed each transcript line-by-line and applied content codes. Differences in coding and proposed changes to the coding template were then discussed and adjudicated via team consensus during weekly meetings, a process known as investigator triangulation which helps to ensure analytic rigor.^{16,29} Results were organized around overarching codes (e.g. "Assessment" and

“Training provision”) and relevant subcodes (e.g. “Assessment: caregiver experience” and “Assessment: home environment”), and we present illustrative quotations to better describe and capture key informant responses. All analysis was performed in Atlas.ti version 8.4 (Atlas.ti, Berlin, Germany).

RESULTS:

Of the four participating agencies, three were not-for-profit and one was for-profit; three were urban and one was rural; two operated on a local scale, one on a regional scale, and one on a national scale. Of the 19 key informants, 11 were RNs and 8 were PTs; 18 were female and 1 was male; 17 were white, 1 was black, and 1 declined to share their race/ethnicity. Key informants had an average of 9.3 years (range: 1.5 to 23.0) of experience in home health and an average age of 45.0 years (range: 28.0 to 63.0). Participating agency and key informant characteristics are summarized in Supplemental Material, table B.1.

I. Importance of Family Caregiver Training

Clinicians universally (19 of 19 respondents) endorsed teaching/training family caregivers as an integral part of their role, stating “*Home care is all about education*” (RN, agency A) and “[*Caregiver training*] is always an expectation whether it's five minutes of my visit or 50 minutes of the visit” (RN, agency B). Clinicians viewed this training as helping to create a safer home environment for the patient by better preparing the caregiver: “*That caregiver is going to be following up, and giving the directions, and giving the assistance when I'm not there*” (PT, agency B.) Additionally, family caregivers were reported to help inform clinicians, providing valuable information about the patient’s current condition, history, and home environment: “*A lot of our patients have family that have been doing this for 30 years and know their meds backwards and forwards...*” (RN, agency D).

II. Cycle of Family Caregiver Training

Clinicians’ descriptions of providing family caregiver training revealed a dynamic and cyclical process, divided into four major phases: Initial Assessment, Education, Reassessment, and Adjustment (Figure 2). During *initial assessment*, clinicians gathered information (via objective and subjective methods) regarding caregivers’ training needs. They then provided *education* to address the most pressing training needs, largely using demonstration and teach-back. *Reassessment* was ongoing throughout the episode as clinicians evaluated caregiver progress. In response to progress, or lack thereof, clinicians performed *adjustment* to the care plan, including changes in education, visit frequency, and involved disciplines.

1. Initial Assessment—The initial assessment of caregiver training needs was described as being informal and holistic (Table 1.1); clinicians reported relying on their intuition, honed via experience in home health, and observations of caregiver, patient, the dynamic between the two, and the home environment. None of the clinicians interviewed reported using a structured assessment tool to guide this process. Caregiver capability (physical ability, knowledge) and engagement (willingness to provide assistance, interest in receiving training) were evaluated via observation and direct questioning (Table 1.2).

Clinicians also ascertained the scope of patients' needs for caregiver assistance (Table 1.3) and attempted to understand the patient/caregiver relationship dynamic (Table 1.4). Observations of the home environment were reported to yield valuable information at both the individual (safety risks requiring caregiver education) and structural level (indicators of socio-economic status and available resources) (Table 1.5).

2. Education—Caregiver education often focused on instruction regarding assistance with nursing/medical tasks (managing medications, wound care, adhering to specific diet) and Activities of Daily Living (transferring and ambulation, bathing, dressing). Clinicians described using demonstration to train caregivers: narrating actions and explaining the underlying clinical reasoning, then requesting teach-back to ascertain understanding and identify areas for clarification (Table 2.1). Clinicians reported tailoring their approach, individualizing instruction to better fit the specific patient and caregiver (Table 2.2). Clinicians noted a lack of effective, structured educational materials and instead created and compiled their own library of training resources, drawing on the internet, external educational companies, their own experience, and resources provided by current and former employers (Table 2.3). Given time constraints and patients' significant clinical and functional needs, clinicians stressed the importance of prioritizing instruction related to the most crucial care needs first, as determined by their clinical judgment, before moving on to other topics in later visits (Table 2.4). Specifically, clinicians reported prioritizing the care needs they deemed most likely to negatively affect patient safety and/or prompt a readmission if left unaddressed.

3. Reassessment—Clinicians reported continuing to monitor caregivers' comfort-level and ability to confidently and competently provide needed assistance throughout the episode (Table 3). Relying on the same modes of assessment described in the Initial Assessment phase, clinicians evaluated the success of previous training efforts at each subsequent visit to the patient's home.

4. Adjustment—Clinicians adjusted their actions and expectations after reassessing caregiver progress. If the caregiver struggled, clinicians described accessing additional structural resources; these included scheduling additional visits, incorporating other disciplines such as social work, and soliciting advice from the broader home health care team (Table 3.2). If prior training seemed effective, clinicians reported educating the caregiver on new topics which, while important, were less critical to patient safety and thus not prioritized in previous visits (Table 3.3). Finally, if the caregiver appeared unwilling or unable to absorb clinician instruction, clinicians stated they would document their efforts to protect against potential legal action (Table 3.4) and consider discharging the patient and/or recommending a transition to an institutional environment (Table 3.5).

DISCUSSION

During semi-structured key informant interviews, home health clinicians (RNs and PTs) affirmed the importance of family caregiver training during home health and described a process of clinician-led training for caregivers comprised of initial assessment, followed by a cycle of education, reassessment, and adjustment. Clinicians reported relying on their

individual experience, for example during informal assessments of caregiver needs and while compiling training materials. Clinicians described engaging the broader care team for assistance when training appeared unsuccessful, for example calling in social work or a more experienced nurse. The perceived success of family caregiver training was reported to help determine visit intensity, service mix, and discharge timing.

Findings support the major components of our conceptual framework (interrelating individual, interpersonal, and structural factors) and suggest necessary additions. In the category of individual factors, participants emphasized not only caregiver capacity but also *willingness* to receive training, which was not included in the original model. Communication and support from the broader care team were noted as an important component of the education and adjustment phases of training, and should be included as meaningful structural factors. Finally, clinicians emphasized that their interactions with the caregiver—particularly, their ability to engage with and educate the caregiver—helped determine the intensity of care provided, suggesting an extension of this model with home health efficiency and outcomes as an additional endpoint.

While there is growing interest in family caregiver education and training across multiple care delivery settings,^{6,30-34} caregiver training is already routinely integrated into home health care delivery. This is likely the result of necessity—clinicians are only present intermittently and patients are often at high risk for readmission,¹ as well as opportunity—clinicians can directly observe the patient/family's home environment and may interact with the caregiver multiple times across a single episode of care.^{20,24} The Agency for Healthcare Research and Quality (AHRQ) has published a guide to patient and family engagement during hospital-to-home care transitions: the IDEAL model.³⁵ While designed to inform actions within the hospital, it is notable that home health clinicians described implementing many of the recommendations contained in this system, including: providing education in plain language which evolves as the patient's needs progress, assessing understanding using teach-back, and identifying and responding to the individual goals, preferences, and concerns of the patient and family. While further exploration is needed to identify the hallmarks of quality patient and family engagement in the home health setting specifically, it is encouraging that home health clinicians have already implemented some of the best practices identified by AHRQ, largely without formal guidance.

Although there are areas of strength in current practices of family caregiver training during home health, the lack of structured support for these efforts is concerning. Clinicians noted that formal educational materials to support their training efforts were often lacking and, as a result, they had to compile their own resources by drawing on previous jobs, paying out-of-pocket for subscriptions to educational services, or relying on publicly-available resources including YouTube videos. The lack of formal, standardized materials at the agency-level suggests that, despite clinicians' best efforts, not all family caregivers will receive the same quality of instruction. This variability is especially troubling given that clinicians identified the success or failure of caregiver training as a determining factor to a number of financially- and clinically-relevant outcomes including visit intensity, service mix, and discharge timing and destination.

Clinicians described relying on informal, holistic evaluations of caregivers' abilities and needs. While clinicians' implicit assessments of the caregiver and home environment are immensely valuable, the lack of standardized assessment introduces the potential for bias³⁶ and for needs to go unnoticed and unaddressed.^{24,37} A 2019 revision to OASIS (OASIS-D) removed an item that queried clinicians about caregiver training needs at the start of care; previously the only national source of such information.³⁸ This change eroded the ability to systematically monitor data on caregiver needs during home health, yet simultaneously created an opportunity to rethink how this information could and should be gathered. CMS should consider reinstating this item, with some important revisions: while the previous OASIS item consisted of granular information related to skills training at a single point in time, information gathered in this study indicates that the most useful tool would incorporate caregiver reports of their own support needs, identify social as well as didactic training needs, and help the clinician track progress over time towards meeting these needs. Given the significant administrative burden faced by home health clinicians, any instrument must be brief to be feasible, but could serve as a valuable tool to facilitate an accurate, nuanced understanding of caregiver needs, to identify opportunities to improve caregiver capability and confidence during home health, and to monitor home health agency compliance with CMS policy mandating access to training for family caregivers.

STRENGTHS AND LIMITATIONS

This qualitative study provides novel information regarding clinician-led training of family caregivers during skilled home health. Using key informant interviews with home health clinicians, we were able to obtain a detailed account of current practice from those tasked with leading these efforts in the home health setting. Several limitations warrant comment. Although we purposively included home health agencies with diversity across several meaningful characteristics, participating agencies and individuals may have differed in meaningful ways from non-participants. For instance, those willing to participate may place greater value/emphasis on family caregiver training. Thus, there may be limited transferability of findings to other types of clinicians/agencies. We employed multiple strategies to increase credibility, reliability, and rigor; including an audit trail, investigator triangulation, and thick description.^{16,29,39} However, as this is a qualitative, descriptive study we cannot comment on causal relationships.

Conclusion

Home health clinicians identified family caregiver training as a crucial component of home health care delivery and reported that the success of training impacted their decision-making around visit intensity, service mix, and discharge timing and destination. However, clinicians contended with a lack of structured assessment instruments or training materials to facilitate their efforts in this space. Family caregiver training is a significant, yet understudied, element of skilled home health with the potential to reduce caregiver burden and improve care outcomes for older adults. Further research is warranted which specifically identifies barriers to this crucial aspect of home health and opportunities to better support clinicians in this work.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

ACKNOWLEDGEMENTS

Funding sources: This work was supported by grants from the Alliance for Home Health Quality and Innovation [no grant number] and the National Institute on Aging [T32AG066576].

REFERENCES

1. March 2019 Report to the Congress. Washington, DC: Medicare Payment Advisory Commission. 2019. http://medpac.gov/docs/default-source/reports/mar19_medpac_entirereport_sec.pdf?sfvrsn=0.
2. Home Health Chartbook 2018: Prepared for the Alliance for Home Health Quality and Innovation. Alliance for Home Health Quality and Innovation & Avalere Health; 2018. http://ahhqi.org/images/uploads/AHHQI_2018_Chartbook_09.21.2018.pdf.
3. Burgdorf J, Arbaje A, Wolff J. Older Adult Factors Associated With Identified Need for Family Caregiver Assistance During Home Health Care. *Home Health Care Management & Practice*. 2019;doi:10.1177/1084822319876608
4. National Academies of Sciences, Engineering, and Medicine. (2016). *Families Caring for an Aging America*. Washington, DC: The National Academies Press. 10.17226/23606.
5. Burgdorf J, Roth DL, Riffin C, Wolff JL. Factors Associated with Receipt of Training Among Caregivers of Older Adults. *JAMA Intern Med*. 4 2019;doi:10.1001/jamainternmed.2018.8694
6. Van Houtven CH, Smith VA, Lindquist JH, et al. Family Caregiver Skills Training to Improve Experiences of Care: a Randomized Clinical Trial. *J Gen Intern Med*. 8 2019;doi:10.1007/s11606-019-05209-x
7. Teri L, Logsdon RG, McCurry SM, Pike KC, McGough EL. Translating an Evidence-based Multicomponent Intervention for Older Adults With Dementia and Caregivers. *Gerontologist*. 10 2018;doi:10.1093/geront/gny122
8. Nuckols TK, Keeler E, Morton S, et al. Economic Evaluation of Quality Improvement Interventions Designed to Prevent Hospital Readmission: A Systematic Review and Meta-analysis. *JAMA Intern Med*. 7 2017;177(7):975–985. doi:10.1001/jamainternmed.2017.1136 [PubMed: 28558095]
9. Chase JD, Russell D, Kaplan DB, Bueno MV, Khiewchaum R, Feldman PH. "Doing the Right Thing": Family Caregivers Managing Medical and Nursing Tasks in the Postacute Home Health Care Setting. *J Appl Gerontol*. 9 2020;733464820961259. doi:10.1177/0733464820961259
10. 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*. 7 2020;doi:10.1016/j.jamda.2020.05.032
11. Burgdorf JG, Stuart EA, Arbaje AI, Wolff JL. Family Caregiver Training Needs and Medicare Home Health Visit Utilization. *Med Care*. 1 21 2021;doi:10.1097/mlr.0000000000001487
12. 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*. 3 2021;doi:10.1111/jgs.17138
13. Medicare and Medicaid Program: Conditions of Participation for Home Health Agencies. Washington, DC: Centers for Medicare and Medicaid Services; 2017. <https://www.federalregister.gov/documents/2017/01/13/2017-00283/medicare-and-medicaid-program-conditions-of-participation-for-home-health-agencies>.
14. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007;19(6):349–357. doi:10.1093/intqhc/mzm042 [PubMed: 17872937]
15. Outcome and Assessment Information Set Guidance Manual. Washington, DC: Centers for Medicare and Medicaid Services. 2016. <https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/HomeHealthQualityInits/Downloads/OASIS-C2-Guidance-Manual-6-17-16.pdf>

16. Bradley EH, Curry LA, Devers KJ. Qualitative data analysis for health services research: developing taxonomy, themes, and theory. *Health Serv Res.* 8 2007;42(4):1758–72. doi:10.1111/j.1475-6773.2006.00684.x [PubMed: 17286625]
17. Malterud K, Siersma VD, Guassora AD. Sample Size in Qualitative Interview Studies: Guided by Information Power. *Qual Health Res.* 2016;26(13):1753–1760. doi:10.1177/1049732315617444 [PubMed: 26613970]
18. Francis Francis JJ, Johnston M, Robertson C, et al. What is an adequate sample size? Operationalising data saturation for theory-based interview studies. *Psychol Health.* 2010;25(10):1229–1245. doi:10.1080/08870440903194015 [PubMed: 20204937]
19. 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. *Journal of Patient Experience.* 2019;doi:10.1177/2374373519869156
20. Irani E, Hirschman KB, Cacchione PZ, Bowles KH. The Role of Social, Economic, and Physical Environmental Factors in Care Planning for Home Health Care Recipients. *Res Gerontol Nurs.* 12 2019:1–8. doi:10.3928/19404921-20191210-01
21. Irani E, Hirschman K, Cacchione P, Bowles K. Home Health Nurse Decision-Making Regarding Visit Intensity Planning for Newly Admitted Patients: A Qualitative Descriptive Study. *Home Healthcare Services Quarterly.* 2018;37(3):211–231. doi:10.1080/01621424.2018.1456997
22. Arbaje AI, Hughes A, Werner N, et al. Information management goals and process failures during home visits for middle-aged and older adults receiving skilled home healthcare services after hospital discharge: a multisite, qualitative study. *BMJ Qual Saf.* 2 2019;28(2):111–120. doi:10.1136/bmjqs-2018-008163
23. Brega A, Schlenker R, Hijjazi K, et al. Study of Medicare Home Health Practice Variations: Final Report. 2002. <https://aspe.hhs.gov/system/files/pdf/72736/epic.pdf>
24. Bradley P Family Caregiver Assessment: Essential for Effective Home Care. *J Gerontol Nurs.* 2003;29(2):29–36. doi:10.3928/0098-9134-20030201-08
25. Cho E A proposed theoretical framework addressing the effects of informal caregivers on health-related outcomes of elderly recipients in home health care. *Asian Nurs Res (Korean Soc Nurs Sci).* 2007;1(1):23–34. doi:10.1016/S1976-1317(08)60006-7 [PubMed: 25030541]
26. Russell D, Burgdorf J, Kramer C, Chase J. Family Caregivers' Conceptions of Trust in Home Health Care Providers. *Research in Gerontological Nursing, Forthcoming.* 2021;
27. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res.* 11 2005;15(9):1277–88. doi:10.1177/1049732305276687 [PubMed: 16204405]
28. Elo S, Kyngas H. The qualitative content analysis process. *J Adv Nurs.* 4 2008;62(1):107–15. doi:10.1111/j.1365-2648.2007.04569.x [PubMed: 18352969]
29. YS L, EG G. *Naturalistic inquiry.* Sage Publications; 1985.
30. Fields B, Rodakowski J, Leighton C, Feiler C, Minnier T, James AE. Including and Training Family Caregivers of Older Adults in Hospital Care: Facilitators and Barriers. *J Nurs Care Qual.* Jan-Mar 2020;35(1):88–94. doi:10.1097/ncq.0000000000000400 [PubMed: 30889081]
31. Fields B, Turner RL, Naidu M, Schulz R, James E, Rodakowski J. Assessments for Caregivers of Hospitalized Older Adults. *Clin Nurs Res.* 7 2020;29(6):382–391. doi:10.1177/1054773818816207 [PubMed: 30526002]
32. Wolff JL, Freedman VA, Mulcahy JF, Kasper JD. Family Caregivers' Experiences With Health Care Workers in the Care of Older Adults With Activity Limitations. *JAMA Netw Open.* 01 2020;3(1):e1919866. doi:10.1001/jamanetworkopen.2019.19866 [PubMed: 31977063]
33. Riffin C, Wolff JL, Estill M, Prabhu S, Pillemer KA. Caregiver Needs Assessment in Primary Care: Views of Clinicians, Staff, Patients, and Caregivers. *J Am Geriatr Soc.* 06 2020;68(6):1262–1270. doi:10.1111/jgs.16401 [PubMed: 32167573]
34. Coleman EA, Roman SP, Hall KA, Min SJ. Enhancing the care transitions intervention protocol to better address the needs of family caregivers. *J Healthc Qual.* 2015 Jan-Feb 2015;37(1):2–11. doi:10.1097/01.JHQ.0000460118.60567.fe [PubMed: 26042372]
35. *Care Transitions from Hospital to Home: IDEAL Discharge Planning Implementation Handbook.* Agency for Healthcare Research and Quality

- (AHRQ). 2013. https://www.ahrq.gov/sites/default/files/wysiwyg/professionals/systems/hospital/engagingfamilies/strategy4/Strat4_Implement_Hndbook_508_v2.pdf
36. Johnson RL, Roter D, Powe NR, Cooper LA. Patient race/ethnicity and quality of patient-physician communication during medical visits. *Am J Public Health.* 12 2004;94(12):2084–90. doi:10.2105/ajph.94.12.2084 [PubMed: 15569958]
37. Feinberg LF. Caregiver assessment. *Am J Nurs.* 9 2008;108(9 Suppl):38–9. doi:10.1097/01.NAJ.0000336412.75742.6e
38. Outcome and Assessment Information Set OASIS-D Guidance Manual. Washington, DC: Centers for Medicare and Medicaid Services.2019. <https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/HomeHealthQualityInits/Downloads/OASIS-D-Guidance-Manual-final.pdf>
39. Korstjens I, Moser A. Series: Practical guidance to qualitative research. Part 4: Trustworthiness and publishing. *Eur J Gen Pract.* 12 2018;24(1):120–124. doi:10.1080/13814788.2017.1375092 [PubMed: 29202616]

KEY POINTS:

- During home health, the perceived success of family caregiver training helps clinicians determine care intensity and discharge timing.

Why does this matter? Policies to support home health clinicians in providing family caregiver training could improve care of older adults.

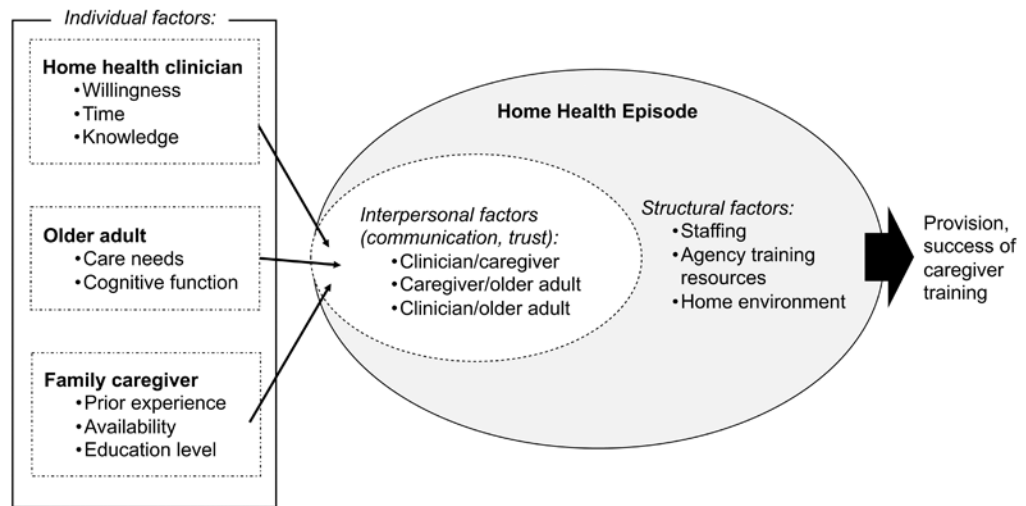


Figure 1:
Conceptual Framework

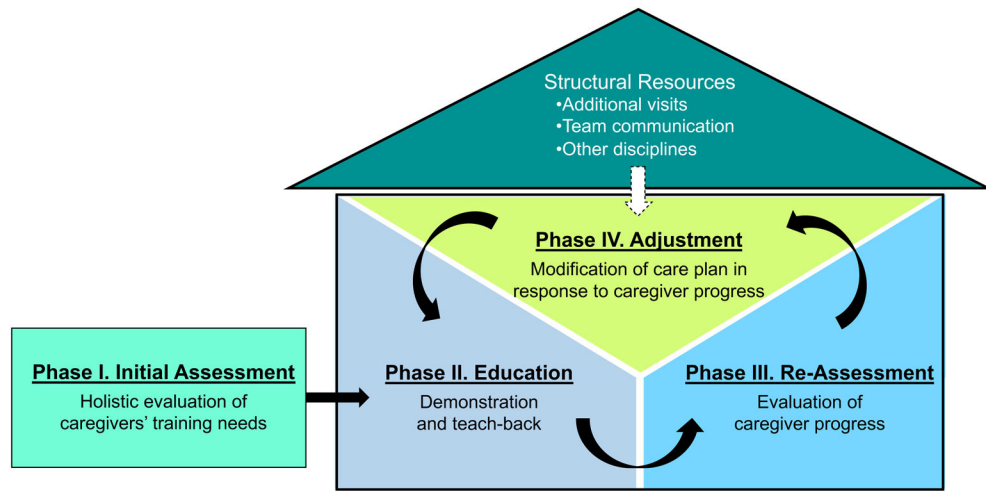


Figure 2:
Cycle of Family Caregiver Training in Home Health Care

Table 1.

Caregiver Training Phase I: Initial Assessment*

<p><u>1.1 The initial assessment of caregiver training needs was informal and holistic</u></p> <p><i>“Trust your gut instincts...you can tell just by some of the body language and the mannerisms of the caregiver and the patient their level of comfort too.” (RN, agency B)</i> <i>“Usually I just look at them, and I can tell.” (RN, agency D)</i> <i>“I can just kind of go in and observe the house for about five minutes and figure out where we’re going. <laughs> What needs to be done.” (PT, agency C)</i></p>
<p><u>1.2 Caregiver capability and engagement were evaluated</u></p> <p><i>“I have a patient say ‘I know my daughter was here today, but she won’t be back.’ Well, that tells me a lot, and they were like a one-hit wonder.” (RN, agency A)</i> <i>“You also have to look at the frailty of the partner or the spouse.” (PT, agency C)</i> <i>“Subjectively I’m looking at ‘How much are they listening to me when I’m talking? How involved are they? Are they feeling anxious?’ And no judgment either way. It just helps me to determine how ready they actually are to be involved.” (RN, agency A)</i></p>
<p><u>1.3 Clinicians ascertained the scope of patients’ needs for caregiver assistance</u></p> <p><i>“A dementia diagnosis would give it away right away, that this person is going to need caregiver training.” (PT, agency A)</i> <i>“I think it begins with a good patient history and understanding their prior level of functioning, what their goals are.” (PT, agency C)</i></p>
<p><u>1.4 Clinicians attempted to understand the existing patient/caregiver relationship dynamic</u></p> <p><i>“I’ll see family dynamics, too, because sometimes a family member will say, ‘Oh, yeah. I’ll do that. I’ll do that,’ but then they’re not in the best relationship.” (RN, agency C)</i> <i>“I first kind of make a broad assumption of kind of the attitude between the two...it can even be hostile or it can be very pleasant.” (PT, agency C)</i></p>
<p><u>1.5 Observations of the home environment yielded valuable information</u></p> <p><i>“You can kind of guess a level of education walking into a house, in how the house is kept... whether they need more training versus not as much.” (PT, agency A)</i> <i>“The difference between going to a million dollar home versus a home that obviously is not...sometimes that can help tune what you need to teach as well.” (RN, agency B)</i></p>

* 18 of 19 clinicians provided responses coded as one or more of the categories above

Table 2.

Caregiver Training Phase 2: Education *

<p><u>2.1 Clinicians described using demonstration and teach-back to train caregivers</u></p> <p><i>"I explain everything that I'm doing first and explain why I'm doing it...I demonstrate it first so they can see how it should be done...and then I have them keep giving return demonstrations until they feel comfortable." (RN, agency D)</i> <i>"I would have them observe first and then I would have them try with me right there, helping as needed and then I would typically come back and observe how they're doing it." (PT, agency A)</i> <i>"I feel like I'm teaching a lot, even more than I realize sometimes because I'm just talking about what I'm doing, and why I'm doing it, why it's important, while I'm doing the skill." (RN, agency C)</i></p>
<p><u>2.2 Clinicians tailored their approach, individualizing instruction</u></p> <p><i>"Sometimes it's just learning style... It's identifying learning preferences." (RN, agency A)</i> <i>"You look very specifically at what the person can or can't handle... So it's very individualized. Very person-centric." (RN, agency B)</i> <i>"You have to learn to be able to kind of bend and be flexible with the background and kind of using teaching and personality to kind of go with that flow." (RN, agency B)</i></p>
<p><u>2.3 Training materials varied significantly between clinicians, even at the same agency</u></p> <p><i>"I try to find legit sites. So it'll be like that company or that particular pump for the IV that they sent out, I will go to that website and find a YouTube video for that." (RN, agency C)</i> <i>"All of us have our own favorite handouts. So you might go into somebody's house, and go, "Oh, yeah, [A] was here." And you see [A]'s favorite exercise sheet there. And then, "Oh, [B] was here," and there's my favorite exercise sheet." (PT, agency B)</i> <i>"The company does have a few [educational materials] but they are definitely not very user friendly...I have my own subscription to MedBridge." (PT, agency C)</i></p>
<p><u>2.4 Clinicians stressed prioritizing instruction related to the most crucial needs first</u></p> <p><i>"It's like 10 things happening there, and I'm like 'Shoot. What do I teach? What do I teach?'...I need to worry about safety first and work my way up through that hierarchy." (RN, agency A)</i> <i>"I try not to do too many things in one visit...because if you do too many teachings in one day it's just too much. It's overwhelming." (RN, agency C)</i> <i>"What's the most high-risk situation here, which is the most critical piece of information, and let's get that done before we move on to something else. Most of the time, people are pretty overwhelmed when they come out of the hospital, as are their caregivers." (RN, agency A)</i></p>

* 19 of 19 clinicians provided responses coded as one or more of the categories above

Table 3.

Caregiver Training Phase 3: Reassessment and Phase 4: Adjustment *

<p>3.1 Clinicians reported continuing to monitor caregivers' comfort-level and ability</p> <p><i>"It's, you know, constantly reassessing... in some situations it can be obvious that they're not carrying over the technique you might be teaching them. It's like, 'Okay. So you really haven't worked on this.' <laughs> 'You really didn't listen last time I was here.'"</i> (PT, agency C) <i>"It changes from visit to visit, and you have to reassess that every time...next time I come can they still teach that back to me? Are they actually retaining this?"</i> (RN, agency A) <i>"If you're having to make more than three visits and you've educated on the same thing and it's still not getting through then you need to reevaluate. Are you teaching the right person? Is there somebody else you could be teaching, or is this even a viable goal for this person?"</i> (RN, Agency C)</p>
<p>3.2 If the caregiver struggled, clinicians described accessing structural resources</p> <p><i>"If they're, like, stumbling and fumbling and oh, I can't remember where this is...that is how I base our visits of how often do we need to come back."</i> (RN, agency B) <i>"I start seeing deficits and, you know, the care that's being provided, then I start thinking, 'Okay. Well, maybe the social worker needs to come in.'"</i> (RN, agency A) <i>"We will work together on... 'what are we going to do about the caregiver?' Especially if there's a problem...So that's more of a team effort, and I would say it's done via our communicating with each other."</i> (PT, agency B)</p>
<p>3.3 If training seemed effective, clinicians reported educating the caregiver on new topics</p> <p><i>"I try to just do one teaching per visit ... once they have shown me that they can do it and they feel comfortable, then I might move on to the next thing."</i> (RN, agency C) <i>"They don't have any questions and they're demonstrating that they know them, then the training-- it's a continuum. It just moves, morphs on to another area."</i> (PT, agency A)</p>
<p>3.4 Clinicians documented their efforts to protect against potential legal action</p> <p><i>"You just document something, you know, 'Offered training to the caregiver. Caregiver not willing to observe during the session. Not receptive to caregiver training' ... you do need to document that, because it's, you know, it's on me in the end."</i> (PT, agency C) <i>"I'm going to do three visits of banging my head against the wall trying to engage them, trying to do caregiver training but I know they're not going to engage but I have to document my attempts... And it basically becomes cover your ass, you know?"</i> (PT, agency C)</p>
<p>3.5 Clinicians considered recommending a transition to an institutional environment</p> <p><i>"If they don't have a caregiver that can be taught and the patient themselves needs a caregiver we shouldn't be taking them under care. They need a higher level of care."</i> (RN, agency A) <i>"If it's obvious the caregiver's not going to get it...you've done all you can do for weeks upon weeks and you need to just document that there's been limited carryover and try and get this patient to a safe situation."</i> (PT, agency C)</p>

* 18 of 19 clinicians provided responses coded as one or more of the categories above

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript