

# “They Are Lost Souls”: Medicare Home Care Nurses’ Perceptions of Medicare’s Inadequate Coverage of Homebound Persons With Alzheimer’s Disease

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## Abstract

Alzheimer’s disease is a major and increasing cause of illness and death in the United States, imposing significant social, economic, and psychological burdens on patients and their caregivers. This article explores the perceptions of Medicare home health nurses as to the impact of Medicare home health requirements on their decisions to admit, treat, cope with, and meet patient care needs of Alzheimer’s disease patients. It presents an exploratory study, which resulted from a gap in the literature review that found only 3 studies and 1 article since 1965. The study is based on interviews of a convenience sample of 37 home care nurses from 5 home health agencies in the New York City metropolitan area. Analysis followed the grounded theory 3-stage coding of interview data: open, axial, and selective coding. This research methodology was used because it was developed for interpreting qualitative data in the absence of a pre-existing theory. Five themes emerged from interviews: (1) Most Medicare home health patients have some level of Alzheimer’s disease (AD). Medicare home care regulations: (2) restrict nurses’ admissions of persons with AD and lack a mandatory evidence-based assessment for AD; (3) restrict the care that nurses can order for persons with AD; (4) do not cover evidence-based non-pharmacological interventions for AD patients; and (5) nurses use 3 coping strategies to deal with the restrictions: most as *conformists*, others as *innovators*, some as *rebels*. Policymakers are urged to consider legislation expanding coverage of home-based, evidence-based non-pharmacological interventions for persons with Alzheimer’s disease; expanding Medicare home care social work services to allow delivery of appropriate services; requiring an evidence-based Alzheimer’s disease assessment at intake and as part of the OASIS; additional reimbursement for home health agencies treating Medicare homebound persons with Alzheimer’s disease.

## Keywords

Medicare home health, Alzheimer’s disease, dementia, home care nursing, mental health, social determinants of health

## Introduction

The purpose of this study was to explore Medicare home health nurses in Medicare-certified home health agencies nurses’ perceptions of the impact of Medicare home health requirements on their decisions to admit and how to treat Alzheimer’s disease patients; their coping strategies; and the overall impact on meeting patient care needs.

Alzheimer’s disease is the most common form of Alzheimer’s disease and related dementias (ADRD) and most common cause of dementia.<sup>1</sup> Alzheimer’s disease (AD) is a major and increasing cause of illness and death in the United States, and internationally, imposing significant social, economic, and psychological burdens on patients and their caregivers.<sup>1,2</sup> According to the Alzheimer’s Association,<sup>1</sup> about 6.7 million Americans, or 1 in 9 people (10.8%) age 65 and older, in 2023 had Alzheimer’s dementia, and estimates

indicate the prevalence is projected to increase as the elderly population increases by 2060.

According to the Centers for Disease Control and Prevention (CDC),<sup>3</sup> as of 2019, 80% of persons with Alzheimer’s disease were community dwelling adults aged 65 and older. Other studies indicate that approximately 25% of these community-dwelling adults use some form of paid home care services and even more use unpaid home care services, including family, friends, and relatives as caregivers.<sup>4</sup> In 2019, approximately 11% of all Medicare Fee for Service

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beneficiaries had claims with a diagnosis Alzheimer's disease and related dementias.<sup>5</sup> Of the over 2.5 million Medicare beneficiaries receiving Medicare home health care, an estimated 30% have Alzheimer's disease and related dementias, with most having Alzheimer's Disease.<sup>4,6,7</sup>

The 30% may be an underestimate because the Medicare Outcome and Assessment Information Set (OASIS), the mandatory national assessment tool for Medicare home health, does not have any evidence-based or other measure within it, to assess for stage or level of either Alzheimer's disease or dementia.<sup>8,9</sup> In addition, one study using data from the OASIS found 26.7% of Medicare home health beneficiaries with memory deficit and/or impaired decision-making and 43.9% with reduced cognitive function.<sup>10</sup> Another study found that 17% of homebound elders have undiagnosed cognitive impairments.<sup>11</sup> Limits in memory, decision-making, and cognitive function all are symptoms of Alzheimer's disease and related dementias.<sup>1</sup> Despite data indicating that an estimated 30% of Medicare home health beneficiaries have Alzheimer's disease and related dementias, with most having Alzheimer's Disease.<sup>4,6,7</sup> Medicare home health claims data indicate only 1.2% of Medicare home health beneficiaries have Alzheimer's disease as their primary diagnosis.<sup>12</sup>

## Literature Review

The literature review used CINAHL, PubMed, Medline, Cochrane Library, Campbell Collaboration, PsycINFO, Sociological Abstracts, and Social Science Abstracts databases with a search period of January 1, 1965, through June 1, 2022, followed by an updated search after the study was conducted covering June 1, 2022, through May 31, 2023. Multiple keywords were used by applying Boolean search strategies: social determinants of health; home care nursing; Medicare home health; Medicare home health and dementia; Medicare home health and Alzheimer's disease; dementia care; Alzheimer's disease; home care and dementia; and home care and Alzheimer's disease. The search found multiple studies on related aspects of home care and Alzheimer's disease and related dementias, but only 3 studies and 1 additional article since 1965 and only one of the studies being since 2015 regarding nurses in Medicare-certified home health agencies perceive the impact of Medicare home health requirements on their decisions to admit and how to treat Alzheimer's disease patients.

The studies on related aspects included studies on Medicare home health patients with dementia as a risk for hospitalization<sup>13</sup> or hospital readmission<sup>6</sup>; home health dementia patients as a risk for early discharge from home health<sup>7</sup>; transitions in care from and between home and hospital by persons with dementia<sup>14</sup>; dementia home care resources<sup>15</sup>; quality of life differences between home-dwelling persons and nursing home residents with dementia<sup>16</sup>; and living arrangements of persons with Alzheimer's disease and related dementias.<sup>17</sup>

Taken together, the 3 studies on home care nurses' perspectives (2007, 2010, 2015), collected and analyzed interview data from a total of 69 home care nurses (as well as 39 home care social workers) from the New York City metropolitan area. The results from all 3 studies were consistent in their findings that nurses view the Medicare home health regulations as resulting in restricted care and unmet needs for patients with Alzheimer's disease.

In the 2007 study<sup>18</sup> the nurses described 3 coping strategies for dealing with the frustration of being unable to appropriately address these patients' needs. One strategy was as a *mechanic*, focusing on a set of limited, authorized tasks within the instructions of their perception of Medicare regulations. At the other extreme was the *caregiver* strategy, with nurses doing as much as possible for Alzheimer's disease patients and their caregivers, despite Medicare regulations. The most frequent coping strategy was being *mediators*, trying to adhere to the Medicare requirements while also trying to negotiate some limited additional care for patients.

In the 2010 study,<sup>19</sup> nurses also described 3 coping strategies for being unable to appropriately address the needs of Alzheimer's disease patients. The study used Merton's theory of anomie to synthesize the coping strategy themes. The 3 strategies were similar though the terminology characterizing them differed from the 2007 study. Overall, nurses (49%) were *innovators*, coping much like the earlier *mediators* group. Another 33% of nurses coped as *conformists*, conforming to the regulations, as did the previous *mechanics* group. The remaining 18% of nurses were characterized as *rebels*, using the same coping strategy as the *caregivers* in the earlier study.

The 2015 study<sup>21</sup> involved interviews of a convenience sample of 29 home care nurses from the New York City metropolitan area between May 2011 and February 2013. The nurses all asserted that the Medicare home health benefit on short-term acute care resulted in restricted care and unmet needs for patients with Alzheimer's disease. Merton's typology was again used to characterize the nurses' coping strategies with 62% (18 of 29) coping as *conformists*, 28% (8 of 29) as *innovators*, and 10% (3 of 29) as *rebels*.

One additional article, referred to earlier, is relevant to discrepancies between the Medicare home health benefit and the needs of Alzheimer's disease patients.<sup>20</sup> While not a study, the article examined the dissonance between the needs and burdens of Alzheimer's disease patients and caregivers, research results of medical and palliative care interventions, and medicalized public policy in the Medicare home health benefit. The article did not focus on nurse, social worker or other formal or informal caregiver perceptions of the Medicare home health benefit, except to note the gap in the literature. The article concluded by recommending the federal government fund a Medicare Palliative Home Care for Alzheimer's disease demonstration project based on the existing cost-savings and quality of life improvement research from the Medicare Hospice Benefit.

## Methods

The article addresses a gap in the literature and presents the results of an exploratory research study of 37 home care nurses from 5 different home health agencies in the New York City metropolitan area between August 1, 2022, and December 31, 2022. The study used interviews to probe nurses' perceptions of the impact of Medicare home health requirements on their decisions to admit and how to treat Alzheimer's disease patients. None of the nurses in the study were in the previous studies of this topic.<sup>18,19,21</sup> The study used a grounded theory approach,<sup>22</sup> which is the research methodology of choice because it was developed for interpreting qualitative data in the absence of a pre-existing theory. In the present study, the existing literature does not provide insight into home care social nurses' perceptions of the impact of Medicare home health requirements on their decisions to admit and how to treat Alzheimer's disease patients.

Participants were selected using a snowball convenience sampling technique, whereby home care social nurses known to the author constituted the initial interviewees and then identified other potential interviewees to the author. In-person interviews were conducted at locations convenient to participants and off-site from where they worked. Interviews averaged 45 minutes and were recorded electronically. No payments or other incentives were given to the interviewees. Nurses were selected as the study focus because they are responsible for the intake; responsible for the admission visit and development and oversight of the plan of care; and have historically been the major source of visits to Medicare home care patients.<sup>23-26</sup>

An interview guide was used to help standardize the data collection, and all participants were assured of anonymity and confidentiality through an informed consent they signed. The interview guide was developed by the author, reviewed by 2 additional experienced qualitative researchers, and pre-tested on 3 home care nurses, who were not part of the study. The interview guide and all questions in the interviews requested the nurses' responses be based on their overall experience as a home care nurse and not specific to the COVID-19 time period. Qualitative analysis began shortly after the initial data were collected and resulted in additional questions and probes that were applied to subsequent interviews, in an ongoing iterative process. Analysis followed the grounded theory 3-stage coding of interview data: open, axial, and selective coding.

Open coding was used to fracture the data to "identify some categories, their properties, and dimensional locations" (p. 97).<sup>26</sup> The coding and classification generated a list of 286 codes. Code and category labels were created, systematically sorted, compared, and contrasted until they were complete, with no new codes or categories produced and all data accounted for. Through axial coding, multiple phenomena were identified from the connected categories

and subcategories. These phenomena included the Medicare decision-making framework; the impact of Medicare requirements on decisions about admitting patients with Alzheimer's disease; the impact of Medicare regulations on deciding the nature and extent of care delivered to meet the needs of patients with Alzheimer's disease; and variations in nurses' coping strategies. Finally, using selective coding, a "story line" was identified and a "story" written that integrated the axial coding phenomena.<sup>26</sup> The story that emerged was home care social nurses' acknowledgment of Medicare requirements restricting admission and care for persons with Alzheimer's disease, including lack of coverage of evidence-based interventions; the impact of Medicare regulations on the nurses' ability to meet the care needs of patients with Alzheimer's disease; and nurses' variations in coping with those restrictions with some being conformists, innovators, and rebels.

In keeping with the grounded theory approach, the data analysis and interpretation were facilitated by analytical and self-reflective memo writing, which helped move empirical data to a conceptual level; expanded and refined the data and codes; developed core categories and interrelationships; and integrated the experiences, interactions, and processes embodied in the data.<sup>32</sup> All initial abstraction, analysis, interpretation, and decisions on whether a saturation level had been reached were done by the author of this article. After the initial process, all abstraction, analysis, interpretations, and saturation decisions were reviewed by 2 additional experienced qualitative researchers, each of whom had a doctoral degree in social work and more than 15 years' experience doing government-funded qualitative research on health care. Any differences were discussed by the 2 external reviewers and the author to reach final decisions used for the study results. All analyses were done using ATLAS.ti software. Saturation was determined by the author in conjunction with the reviewers to determine when, through interviewing the point in a research process had been reached where we believed enough data had been collected to draw/conclude relevant themes, and any further interviews would not produce value-added insights. The author and 2 external reviewers agreed that the Merton typology of *conformists*, *innovators*, and *rebels* most appropriately characterized the major coping strategies of nurses. Any differences were discussed by the 2 external reviewers and the author to reach final decisions used for the study results. All analyses were done using ATLAS.ti software.

## Study Participants

Limited demographic data were collected from study participants using a short survey. The results appear in Table 1. Overall, the nurses were 45 to 55 years old (76%); female (81%); Caucasian, non-Hispanic (78%); had 1 to 5 years of home care experience (67%); and had an average caseload of 20 to 25 patients (78%). Statistical analysis of the demographic

**Table 1.** Home Care Nurse Participant Demographic Characteristics.

| Characteristic             | Number | Percent |
|----------------------------|--------|---------|
| Gender                     |        |         |
| Male                       | 7      | 19      |
| Female                     | 30     | 81      |
| Race/Ethnicity             |        |         |
| Caucasian, Non-Hispanic    | 29     | 78      |
| Hispanic                   | 3      | 8       |
| African American           | 3      | 8       |
| Asian American             | 2      | 6       |
| Age range                  |        |         |
| >55                        | 3      | 8       |
| 45-55                      | 28     | 76      |
| 36-44                      | 3      | 8       |
| 25-35                      | 3      | 8       |
| Years as a home care nurse |        |         |
| >10                        | 3      | 8       |
| 6-10                       | 7      | 19      |
| 1-5                        | 25     | 67      |
| <1                         | 2      | 6       |
| Average patient caseload   |        |         |
| 26-30                      | 3      | 8       |
| 20-25                      | 29     | 78      |
| <20                        | 5      | 14      |

variables' impact on study outcomes was not done due to the qualitative nature of the study. The demographic characteristics of the sample could not be compared to national data on home care nurses to determine degree of representativeness because there is no such database nationally.<sup>19</sup>

## Results

Five themes emerged from interviews: (1) Most Medicare home health patients have some level of Alzheimer's disease (AD). Medicare home care regulations: (2) restrict nurses' admissions of persons with AD and lack a mandatory evidence-based assessment for AD; (3) restrict the care that nurses can order for persons with AD; (4) do not cover evidence-based non-pharmacological interventions for AD patients; and (5) nurses use 3 coping strategies to deal with the restrictions: most as *conformists*, others as *innovators*, some as *rebels*.

### Most Medicare Home Health Patients Have Some Level of Alzheimer's Disease

"We see them [patients with Alzheimer's disease and dementia] every day. They are lost souls," said Nurse EF. She is one of the 37 nurses who said most of their Medicare home health patients have some level of Alzheimer's disease. Nurse HL agreed noting, "They all have some level of Alzheimer's [disease]. We do not assess for it [Alzheimer's disease or any

form of dementia] so it is hard to give a professional answer, but I'd say most are at the moderate level on admission." Other nurses interviewed varied in the extent of their caseloads that had patients with some level of Alzheimer's disease with percentages ranging from Nurse KL estimating, "Oh, I have a lot, I'd say about 30%, maybe more of my cases" to Nurse TF estimating "Oh, it is easily 50% or so." These percentages are consistent with the various studies cited earlier in this article with estimates of 30% or higher when under-reporting was considered.<sup>4,6,7,10</sup>

### Medicare Home Care Regulations Restrict Nurses' Admissions of Persons With Alzheimer's Disease and Lack a Mandatory Evidence-Based Assessment for Alzheimer's Disease

Ninety-two percent of nurses interviewed (34 of 37) indicated they found the Medicare home health skilled care and homebound requirements limited their ability to admit and retain home care patients with Alzheimer's disease and that neither the OASIS nor any other evidence-based measure was used to assess patients for Alzheimer's disease or any other form of dementia, as noted earlier in this article.<sup>8,9</sup> The remaining 8% (3 nurses) said they could not comment because they had not done intakes or admission visits. One of the 3 nurses interviewed with more than 10 years home care experience gave the best summary of the admissions challenge:

As I said, we have a lot of patients with Alzheimer's disease. We know it, because of the symptoms, though it would be better if we professionally assessed them, but OASIS doesn't have that [type of assessment] and our agency, I think most agencies, don't have their own assessment tool. But, in addition, there are a lot more people with Alzheimer's disease that get referred to us that we cannot accept a t intake or on the admission visit because they do not meet the Medicare skilled care or homebound requirements. And then there are some we admit who are marginal [in terms of eligibility] and we must discharge them early because they turn out not to need skilled care or are not homebound. It is a shame. These people need help, and many are poor and cannot pay for it on their own. They have a need, if only for home health aides to help with ADLS [activities of daily living] or social work for their isolation, or depression or memory or cognitive issues. Medicare won't cover that; there needs to be a skilled care need like for nursing or physical therapy. There is a need, but it goes unmet. Nurse AL

According to the Medicare Benefit Policy Manual,<sup>24</sup> Medicare home health requires that a patient must have a skilled care need for nursing, physical therapy, speech therapy or ongoing occupational therapy to receive any services. Having a need for only home health aides or social work services, or both, is considered custodial care and makes the person ineligible. In addition, the prospective patient must be homebound, which Medicare defines an individual as homebound if leaving the home requires substantial effort or

assistance, and if this limitation is due to an illness or injury. The individuals who satisfy this definition leave home briefly and infrequently or leave only when in need of medical care.

According to the Alzheimer's Association,<sup>1</sup> and 92% of the nurses interviewed, Alzheimer's patients may be mobile and able to leave their home on their own because their issues, depending on their disease level, are primarily psychological or cognitive and do not affect their physical mobility. In such cases the persons do not initially or ongoing (after admission) meet the Medicare homebound or skilled care requirement or both, even though they may need home health aide assistance with ADLs in their home or social work assistance in coping with their cognitive or psychosocial issues. For those admitted who subsequently do not meet these requirements, the result may be early discharge, which several studies have found to increase the risk for rehospitalization.<sup>6,7,13</sup>

### ***Medicare Home Care Regulations Restrict the Nature and Extent of Care Nurses Order for Persons With Alzheimer's Disease***

Almost all nurses (95%, or 35 of 37) agreed that they feel restricted in what services they can provide to those persons admitted with Alzheimer's disease,

We can't give them social work services because Medicare limits the ability to do individual or group therapy or even case management, which is what they need. They also need home health aides, but we can't order too much [home health] aide care if they only have a limited skilled care need because either our supervisors will question it or Medicare may deny the claim. It is frustrating because these are the services most of these patients need. We must be very careful on what we put in the plan of care. Nurse TB

The Medicare Benefits Policy Manual<sup>25</sup> confirms the nurse's comments on the limitations of social work coverage.

I had an Alzheimer's patient. I ordered significant [home health] aide care and some social work visits, but I was only making a nursing visit once a week. Their [Medicare] claim was denied because they questioned whether there was a need for skilled care. Ultimately my [nursing supervisor] criticized me and we discharged the patient. Did they have a need for care, well, yes. Could we meet it, no. Nurse HG

### ***Medicare Home Care Regulations Do Not Cover Evidence-Based Non-pharmacological Interventions for Persons With Alzheimer's Disease***

All nurses interviewed agreed the Medicare home health does not cover evidence-based non-pharmacological treatments for persons with Alzheimer's disease.

We learn about these [non-pharmacological evidence-based] interventions in nursing school or in CEU [Continuing Education Unit] courses we are required to take. Alzheimer's is pervasive so we get educated on these interventions, but we cannot use them. Why? Medicare won't cover them, even ones we try to do as nurses, though many have been developed using social workers. We either get our [nursing] supervisor stopping us, or we do it and the claim is denied. It doesn't make any sense. The patient has the need and we, as skilled care nurses, are using evidence-based interventions ourselves or with social workers so why isn't it covered skilled care? Nurse MB

Nurse YH observed:

This is so typical. We even have it with some patients who have other diagnoses. I had this patient. Her primary diagnosis wasn't Alzheimer's disease. I thought it should have been but that doesn't get us as much money from Medicare compared to a more traditional medical primary diagnosis. So, I went along, and used the more traditional medical diagnosis. This client had depression and anxiety in addition to their Alzheimer's. That is very typical. They had an 82-year-old spouse caring for them who was experiencing all this caregiver burden. I thought they could use some separate or combined, you know spousal-based, therapy or that at least the caregiver could benefit from group therapy with a group of other caregivers that were experiencing the same issues. I knew of several evidence-based interventions for this kind of spousal intervention, but my supervisor said it would not be covered by Medicare home health. Then I tried to refer the caregiver to an outpatient mental health agency where they did this kind of intervention, but the agency told me Medicare [Part B] does not cover it, even though it is evidence-based, so they'd need to private pay, and they said it was the same if the patient wanted this kind of intervention outpatient. How frustrating is this? Nurse YH

A good number of these [evidence-based] interventions include what we, nurses, are supposed to do in addition to direct medical care like wound care. It is part of our role in educating the patient and often their caregivers on how to deal with their condition, their situation. But it takes time, and our supervisors watch the length of our visits closely. It affects productivity and finances. I've been told multiple times not to spend so much time because of the productivity impact, but they [the supervisor] also have told me that Medicare will probably deny the claim if they see too much education and training in the documentation, even if we are using an evidence-based protocol. Does this make any sense? Not to me. Nurse DW

### ***Nurses Use Three Different Coping Strategies to Deal With the Restrictions: Most as Conformists, Others as Innovators, and Some as Rebels***

As noted above, many of the nurses were frustrated with their inability to admit and properly treat persons with Alzheimer's disease. In the interviews, each nurse was asked how they coped with these frustrations. Three major coping strategies emerged, which the researchers identified using

Merton's typology of conformists, innovators, and rebels. In this typology,<sup>19</sup> the *conformists* focus on a set of limited, authorized tasks within the instructions of their perception of the Medicare regulations. At the other extreme are the *rebels*, *doing* as much as possible for Alzheimer's disease patients and their caregivers, despite the Medicare requirements. In the middle are the *innovators*, trying to adhere to the requirements while trying to negotiate some limited additional care for patients. These nurses are willing to take more risks than the *conformists*, but not as many as *rebel* nurses. They tend to give some recognition to Alzheimer's disease in their plan of care, if not as a diagnosis; provide more care for longer periods than the *conformists*, though not as extensive as the *rebels*; and actively work with the family on post discharge resources, though rarely get personally involved post discharge. At most, they are playing a balancing game.

### The Conformist Strategy

A majority of the nurses interviewed (54%, or 20 of 37) were *conformists*. Some exemplary comments from these nurses:

I care for these people [the Alzheimer's disease patients] but I am not going to risk my job, so I go by the book [of Medicare regulatory compliance]. Nurse WS

I do what I can but there are limits and I abide by those limits. My job as a nurse is primarily medical and many of these [Alzheimer's disease] patients do not have medical needs or only marginal needs. I'm not going to deal with their psychological or cognitive needs. That is not my role. The regulations say so. Nurse JM

I am trained to do nursing interventions. That is what I do. I know these patients have many other needs but Medicare [home health] really isn't designed for what they need. It is for acute skilled care medical needs so that is what I do. I turn my head to the rest of their needs. I know that sounds cruel, but it helps me get through the day. Nurse LT

### The Innovator Strategy

Thirty-two percent of nurses interviewed (12 of 37) were *innovators*. Some exemplary comments from these nurses:

These people [with Alzheimer's disease] have needs so I try to be as flexible as possible. I make a lot of referrals to social workers. I know they are limited in what they can do but it is the least I can do to try to help because, as a nurse, I need to watch my boundaries. Nurse JV

I make a lot of calls to try to get outside services in there. I think it helps and makes me feel better at night. Not much more I can do as a nurse, but I feel it helps even though some might not consider it clinical. Nurse LS

I tend to spend a bit more time on my visits to these patients and their caregivers. I can't spend too much time, otherwise my

supervisor might start micromanaging my productivity numbers. It is a little more time. I hope it helps. I can't go too far. It is too risky. Nurse LT

### The Rebel Strategy

Fourteen percent of nurses interviewed (5 of 37) were *rebels*. Some exemplary comments from these nurses:

I can't live with myself seeing these patients' needs and our ignoring them because Medicare is so restrictive. I spend a lot more time on my visits with these patients. I make more nursing visits to them. I get an occasional reprimand from my supervisor, but it is worth that risk. Why are we here anyway. We are here to care for people; to meet their needs. Nurse TK

I'll be honest with you. I do a lot in my own time with some of these patients and their caregivers. I make calls to them and, yes, I do visits as me, not as the paid home care nurse. I could get in trouble. It is not allowed in my agency, I guess not allowed in any agency, but I feel it is the right thing to do. Nurse FA

I do a lot of joint visits with social workers and bill them as nursing visits. I act as a cover for them [the social workers] so they can do some real therapy or case management and not have to worry about billing it and getting rejected by management or Medicare. Is it illegal or inappropriate. I guess maybe one or both, but I can't stand seeing these patients needs go unmet. Nurse BC

### Limitations

The study was a qualitative, exploratory study. As such it does not address causality and has several limitations including: small sample size, though larger (n = 37) than some other studies on the topic; lack of random sampling for sample selection; use of a sample of home care nurses only from 5 agencies in the New York City metropolitan area; and lack of a randomized controlled trial experimental design to test specific interventions against a control group, though this was not an intervention study.

### Discussion

Despite its limitations, the study does begin to address a gap in the literature and policy by exploring nurses' perceptions of the impact of Medicare home health requirements on their decisions to admit, treat, and meet the needs of persons with Alzheimer's disease and their coping strategies used to deal with Medicare limitations. While not designed as a direct comparison to the prior studies,<sup>18-21</sup> the present study indicates that there are limited options for nurses to meet the needs of ADRD patients receiving home care.

There are evidence-based solutions to address the nurses' perceptions of inadequate assessment and treatment for persons with Alzheimer's disease, if policymakers are willing to mandate their use. In terms of assessment, there are multiple

assessment tools supported by studies demonstrating their validity and reliability.<sup>27</sup> Many of the assessment tools are brief and thus easily incorporated into nationally required OASIS, which as the nurses observed, even in its newest version, does not have any required assessment of Alzheimer's disease or dementia.<sup>8,9</sup>

In terms of treatment, there are multiple evidence-based, non-pharmacological (psychosocial) interventions for persons with Alzheimer's disease, most of which have been validated in multiple randomized controlled trials funded by the federal government but which, as the nurses observed, are not covered by Medicare home health.<sup>11,28-30</sup> Furthermore, even if such interventions were covered, as the nurses observed, their implementation would not be feasible because of the Medicare home health restrictions on covered social work services.<sup>25,31</sup> As a result, the expansion of Medicare home health social work coverage would be necessary to effectively expand such treatment.

There also are several options to consider for meeting the currently unmet needs of persons with Alzheimer's disease who do not, initially or ongoing, meet the skilled care or homebound requirement. As the nurses noted, failure to meet these requirements results in unmet needs and costly hospital and home care readmissions because patients either are rejected at admission or admitted and result in an early discharge. One option is to create a separate Medicare Alzheimer's disease home care benefit. Such a benefit would not have a skilled care or homebound eligibility requirement. It would require that the Medicare beneficiary be living at home and their level of care and reimbursement would be based on a professional assessment of their stage or level of Alzheimer's disease, using an evidence-based measure, and corresponding plan of care. The plan of care could include skilled care or only social work and/or home health aide. Such a policy option would result in Medicare home health covering longer-term home care for persons with Alzheimer's disease. Another option is to create a separate carve out for such cases, with its own reimbursement within the existing Medicare home health payment system using the same principles. Congress could authorize funding for feasibility or demonstration studies for one or both of these options, much as they did for the Hospice Medicare Benefit, Program of All-Inclusive Care for the Elderly (PACE), and other programs.<sup>32-34</sup>

## Conclusion

The study adds credibility to the need for Congress to enact several policy changes. These would include legislation which would: expand coverage of home-based, evidence-based, non-pharmacological (psychosocial) interventions for persons with Alzheimer's disease; expand Medicare home care social work services to allow delivery of appropriate services; require an evidence-based Alzheimer's disease assessment at intake and as part of the OASIS; and explore expansion of reimbursement for home health agencies treating persons with Alzheimer's

disease and related dementias who do not meet the homebound or skilled care requirements. Given these data it seems policymakers should immediately consider such legislation.

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